THE ILLNESS EXPERIENCE OF HIV-INFECTED LOW-INCOME COLOURED MOTHERS IN THE WINELANDS REGION: THEORETICAL AND PRACTICAL IMPLICATIONS

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DECLARATION

I, the undersigned, hereby declare that the work contained in this dissertation is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

Signature: _____ **Date: _____**

ABSTRACT

Statistics show that young, heterosexual, low-income women are the fastest growing HIV-infected population in South Africa and in the rest of the world. Despite the rapidly growing numbers of women with HIV (human immunodeficiency virus) and AIDS (acquired immune deficiency syndrome), there is a scarcity of research that focuses primarily on how poor minority and disadvantaged women of colour experience being HIV-positive, how these women actually live and cope with their diagnosis. Furthermore, no research studies on minority groups, such as the Coloured women in the Western Cape, exploring these issues have been reported. Consequently, there is an urgent need for research studies in South Africa to explore the range of discourses revealed by low-income and minority women regarding their lives and experiences of HIV/AIDS, in order to generate understanding and knowledge which could contribute to possible interventions, support and care.

The present study aimed to: 1) explore the psychosocial concerns and mental health needs of HIV-infected low-income Coloured mothers in everyday life; 2) construct a testable Grounded Theory regarding the illness experience of low-income Coloured mothers; and 3) recommend guidelines for health workers. The study was a systematic analysis and documentation of how the illness (HIV/AIDS) was constructed in narratives of one particular group of women in South Africa.

Eleven suitable and willing HIV-infected Coloured mothers were recruited by means of convenience and theoretical sampling. The research study was conducted within a social-constructionist framework where the focus was on how HIV-infected, low-income Coloured women make sense of their world and illness experience. Grounded Theory was applied within the framework of qualitative research to analyse the data and to explore the participants' constructions of the illness. As qualitative measure, a semi-structured in-depth interview schedule was developed according to Grounded Theory protocol. To reach the aims of the present study, questions focused on specific behaviours, experiences, thoughts and feelings that related to living with a positive HIV-diagnosis.

In the participants' accounts of their illness experience, two dominant discourses were identified: a discourse of HIV/AIDS, within which the illness was constructed as an stigmatised, incurable and deadly illness; as a shameful illness that someone should be blamed for; and as being associated with secrecy, silence, separation, pain and suffering, loss, and loneliness, as well as a discourse of mothering, what it means to be a "good" woman/mother; constructed as someone that should primarily take care of her children and family, and not be separated from them, or neglect or abandon them through illness or death. It is suggested that the two dominant discourses found in the participants' accounts of their illness experiences, namely the meaning of HIV/AIDS as an illness (a stigmatised, incurable, and deadly illness, a shameful and blameworthy illness, an illness of secrecy, silence, separation, pain and suffering, loss, and loneliness), and the imperatives of mothering, what it means to be a "good" woman/mother (the primary caregiver of children, someone who is connected, physically strong, healthy and productive, and someone who is able to cope with her caregiving responsibilities even when in distress herself) are irreconcilable.

It seems that these distressing and disempowering experiences of being HIV-infected, while also being a primary caregiver and mother of children, caused the participants in the present study severe psychological distress and suffering. Given these discourses and the context of the participants' lives within their specific socio-economic circumstances, namely their lack of emotional and social support from friends and family, abusive relationships, substance abuse, economic hardships, absence of treatment options, as well as their experience of an incapacitating, incurable, stigmatised illness causing them severe physical and psychological distress, it was argued that the majority of the participants in the present study were in some state of depression and were in need of psychosocial support and mental healthcare.

The use of the term 'Coloured' is subject to controversy. It is perceived by some as derogatory, whilst others argue the significance of a 'Coloured' identity. Here and throughout the term 'Coloured' will be used descriptively of a particular cultural community.

OPSOMMING

Statistiek toon dat jong, heteroseksuele, lae-inkomste vroue die MIV-geïnfekteerde populasie is wat die vinnigste in Suid-Afrika en die res van die wêreld toeneem. Nieteenstaande die vinnig toenemende getalle van vroue met MIV (menslike immuniteitsgebreksvirus) en VIGS (verworwe immuniteitsgebreksindroom), is daar ‘n gebrek aan navorsing wat in hoofsaak fokus op hoe arm en agtergestelde gekleurde vroue dit beleef om MIV-positief te wees, hoe hierdie vroue werklik met hul diagnose saamleef en dit hanteer. Verder is geen navorsingstudies oor minderheidsgroepe, soos die Kleurlingvroue in die Wes-Kaap, wat hierdie kwessies ondersoek het, gerapporteer nie. Gevolglik bestaan daar ‘n dringende behoefte dat navorsingstudies in Suid-Afrika ondersoek sal instel na die verskeidenheid diskoerse wat lae-inkomstevroue uit minderheidsgroepe ten opsigte van hul lewens en ervarings van MIV/VIGS aan die lig bring, ten einde begrip en kennis voort te bring wat tot moontlike intervensies, ondersteuning en sorg kan bydra.

Die huidige studie het beoog om: 1) die psigososiale kwellinge en geestesgesondheidsbehoeftes van HIV-geïnfekteerde lae-inkomste- Kleurlingvroue in die daaglikse lewe te verken; 2) ‘n toetsbare Gegronde Teorie aangaande die siektebelewenis van lae-inkomste- Kleurlingmoeders te konstrueer; en 3) riglyne vir gesondheidwerkers aan te beveel. Die studie was ‘n sistematiese ontleding en dokumentering van hoe die siekte (MIV/VIGS) in vertellings van ‘n bepaalde groep vroue in Suid-Afrika gekonstrueer is.

Elf geskikte en gewillige MIV-geïnfekteerde Kleurlingmoeders is deur middel van gerieflikheid- en teoretiese steekproefneming gewerf. Die navorsingstudie is uitgevoer binne ‘n sosiaal-konstruksionistiese raamwerk waar die fokus was op hoe MIV-geïnfekteerde, lae-inkomste- Kleurlingvroue sin maak van hul wêreld en siektebelewenis. Gegronde Teorie is binne die raamwerk van kwalitatiewe navorsing toegepas om die data te ontleed en die deelnemers se konstruksies van die siekte te verken. As kwalitatiewe meetinstrument is ‘n semigestruktureerde, diepgaande onderhoudskedule ooreenkomstig Gegronde Teorie-protokol opgestel. Ten einde die oogmerke van die huidige studie te

bereik, het vrae gefokus op spesifieke gedrag, ervarings, gedagtes en gevoelens wat verband hou met saamleef met ‘n positiewe MIV-diagnose.

Twee dominante diskoerse is in die deelnemers se weergawes van hul siektebelewenisse geïdentifiseer. Die eerste was ‘n diskoers van MIV/VIGS, waarbinne die siekte gekonstrueer is as ‘n gestigmatiseerde, ongeneeslike en dodelike siekte; as ‘n skandelike siekte waarvoor iemand die skuld moet dra; en as ‘n siekte wat geassosieer word met geheimhouding, stilte, skeiding, pyn en lyding, verlies en eensaamheid. Die tweede dominante diskoers wat geïdentifiseer is was ‘n diskoers van moederskap, wat dit beteken om ‘n “goeie” vrou/moeder te wees; dit is gekonstrueer as iemand wat in hoofsaak haar kinders en gesin behoort te versorg, en nie van hulle geskei behoort te wees nie, of hulle vanweë siekte of dood behoort te verwaarloos of te verlaat nie. Daar word voorgestel dat die twee dominante diskoerse wat in die deelnemers se weergawes van hul siektebelewenisse bespeur is, naamlik die betekenis van MIV/VIGS as ‘n siekte (‘n gestigmatiseerde, dodelike en ongeneeslike siekte, ‘n skandelike siekte waarvoor iemand die skuld moet dra, ‘n siekte van geheimhouding, skeiding, pyn en lyding, verlies en eensaamheid), en die gebiedende opdragte van moederskap, wat dit beteken om ‘n “goeie” vrou/moeder te wees (die primêre versorger van kinders, iemand wat verbonde, fisiek sterk, gesond en produktief is, en iemand wat in staat is om haar versorgingsverantwoordelikhede te hanteer selfs wanneer sy self in nood verkeer), onversoenbaar is.

Dit wil voorkom of hierdie pynlike en ontmagtigende ervarings van MIV-geïnfekteerd te wees asook ‘n primêre versorger en moeder van kinders te wees, ernstige psigologiese kwelling en lyding vir die deelnemers aan die huidige studie veroorsaak het. Gegewe hierdie diskoerse en die konteks van die deelnemers se lewens binne hul spesifieke sosio-ekonomiese omstandighede, naamlik hul gebrek aan emosionele en maatskaplike ondersteuning van vriende en familie, afbrekende verhoudings / verbale mishandeling, alhohol- en dwelmmisbruik, ekonomiese swaarkry, afwesigheid van opsies wat behandeling betref, asook hul belewenis van ‘n verswakkende, ongeneeslike, gestigmatiseerde siekte wat ernstige fisieke en psigologiese nood vir hulle veroorsaak het, is aangevoer dat die meerderheid van die deelnemers aan die huidige studie in ‘n depressietoestand was en psigososiale ondersteuning en geestesgesondheidsorg benodig het.

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DEDICATED TO ALL THE WOMEN AND MOTHERS WITH HIV/AIDS IN SOUTH AFRICA WHO ARE SUFFERING IN SILENCE

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CHAPTER 1

Introduction and motivation

1.1 Introduction

Statistics show that young heterosexual women are the fastest growing HIV-infected population in South Africa and in the rest of the world (Kimerling, Armistead & Forehand, 1999; UNAIDS/WHO, 2004; Whiteside & Sunter, 2000). Despite the rapidly growing numbers of women with HIV (human immunodeficiency virus) and AIDS (acquired immune deficiency syndrome), a lack of research still exists about the psychological and social effects of the illness on women in general, and mothers in particular (Catz, Gore-Felton & McClure, 2002; Kalichman, Graham, Luke & Austin, 2002; McPherson, 2000; Sarna, Van Servellen, Padilla & Brecht, 1999; Seidel, 1998; Vetten & Bhana, 2001). Apart from the pain and distress caused by the physical symptoms of the illness itself and by related opportunistic infections, women with HIV/AIDS experience a wide range of social, emotional and psychiatric problems that are accompanied by numerous personal and social losses (Martinez, Israelski, Walker & Koopman, 2002). The psychosocial distress experienced by women with HIV/AIDS can have a detrimental effect on their mental well-being, social functioning and ability to cope with their illness condition and daily lives.

In addition, there are inadequate resources to meet these women's medical and psychosocial needs, especially disadvantaged and low-income women. The incidence of women with HIV/AIDS globally is concentrated in disadvantaged women with lower socio-economic status (Catz et al., 2002; Hudson, Lee & Portillo, 2003; Sowell, Moneyham & Aranda-Naranjo, 1999) and the illness has become a leading cause of death among women in their reproductive years (Adler & Coriell, 1997; Bradshaw, Groenewald, Laubscher, Nojilana, Norman, Pieterse & Schneider, 2003; Kimerling et al., 1999). Therefore, most women living with HIV/AIDS confront not only the challenges and distress

associated with this chronic and life-threatening illness, but also those stressors related to their social/family responsibilities and living conditions.

Thus, an urgent need exists for HIV/AIDS research studies focusing on the psychosocial distress and mental health needs of disadvantaged and low-income women, of women in their reproductive years and women with children. By taking into account the whole bio-psychosocial illness experience of women with HIV/AIDS, integrated treatment approaches can be planned and implemented, which can provide quality medical and mental healthcare as well as social support for women living with HIV/AIDS.

1.2 Women and HIV/AIDS: prevalence, risk factors and treatment issues

According to the 2004 UNAIDS/WHO (2004) update on the epidemic, women were increasingly affected by HIV/AIDS and made up more than half of all infected adults worldwide. Sub-Saharan Africa, home to just over 10% of the world's population, had almost 70% of the total of HIV-positive people worldwide (39.4 million). Adult women made up nearly 60% (13.3 million) of the 25.4 million people with HIV or AIDS in this region (UNAIDS/WHO, 2004). In 2004, an estimated 3.1 million people in the region became newly infected, while approximately 2.3 million died of AIDS. It is important to note that the gap between men and women continued to increase worldwide, with an estimated 13 women living with HIV for every 10 men, but in parts of sub-Saharan Africa the estimate was 36 women living with HIV for every 10 men (UNAIDS/WHO, 2004).

Worldwide, women between 20 and 40 years are considered to be the most vulnerable for contracting HIV/AIDS – this is also the age group most central to the labour force, to child-bearing, to caring for the dependent young and old, and to marshalling and managing the resources for addressing the AIDS epidemic (Treichler, 1999). Schable et al. (cited in Murphy, Marelich, Dello Stritto, Swendeman & Witkin, 2002) and Sowell et al. (1999) confirmed that the majority of women diagnosed with HIV infection were women of child-bearing age (16 to 44 years).

Globally, heterosexual transmission is the most common route of HIV transmission to women. In sub-Saharan Africa, young women between 15 and 24 years are 2.5 times more likely to be infected with HIV than young men (UNAIDS/WHO, 2004). The increased risk for women to become infected via sexual intercourse is related to female anatomy and physiology, and various sociocultural factors, such as poverty, low socio-economic status, violence and gender issues (Ackermann & De Klerk, 2002; Gaskins, 1999; Morokoff, Mays & Coons, 1997). Ackermann and De Klerk (2002) emphasised that intervention and support programmes for women would not be effective if they failed to take into account the reality of women's lives and the special risk factors that make them vulnerable to HIV/AIDS. It is clear, therefore, that the heterosexual transmission of HIV in women should be a special concern for all health professionals/workers.

The results from an antenatal survey conducted by the South African Department of Health in October 2004 indicated that between 6.29 and 6.57 million South Africans were HIV-infected (South African Department of Health, 2005). This correlated with the UNAIDS/WHO figure of an HIV prevalence rate of 10% across the entire South African population (46 million) (UNAIDS/WHO, 2004). As in the rest of sub-Saharan Africa, the fastest growing number of new infections was in young women. The largest survey ever of South African youth (11 904 participants), conducted by the University of Witwatersrand's Reproductive Health Research Unit (RHRU), found that among the 10.2% of South African youth who were HIV-infected, 77% were young women (RHRU, cited in Ndaki, 2004). This survey indicated that by the age of 22 one in four South African women had HIV. A new study has revealed that young South African women are in the frontline of the HIV/AIDS epidemic, with nearly one in four women aged 20 to 24 testing HIV-positive compared to one in 14 men of the same age (Ndaki, 2004).

The 2004 antenatal survey of women attending public antenatal clinics in South Africa conducted by the Department of Health indicated that HIV prevalence among pregnant women was 29.5%, which represented a statistically significant increase over the figure of 27.9% observed in 2003 (South African Department of Health, 2005). Almost 40% of the

women aged between 25 and 29 years old were HIV-positive. Women in their early 20s and early 30s showed a lower prevalence rate at about 30%, whereas older women (over 40) and teenagers had prevalence rates under 20% (South African Department of Health, 2005). The Nelson Mandela and Human Sciences Research Council's study of HIV/AIDS (Shisana, 2002) found that 18.5% of women aged 15 to 49 years living in the Western Cape were HIV-infected. Although there are differences in the statistical data of the above surveys and studies, they all clearly show that women, and in particular women of lower socio-economic status, are at high risk for contracting HIV/AIDS.

The majority of HIV-infected women in South Africa, as in other developing countries, acquired the virus through heterosexual contact. According to Galloway (2004) some studies also indicated that even when women chose to stay faithful to one partner, they were often infected by that very partner. Some of the social factors that are thought to put South African women at risk for HIV infection by their partners are domestic abuse, economic dependence and male control of sexuality (Ackermann & De Klerk, 2002; Leclerc-Madlala, 2000; Miles, 1995). Abdool-Karim et al. (cited in Leclerc-Madlala, 2001) identified some key contextual factors affecting the vulnerability to HIV infection of women living in Kwazulu-Natal, which included lack of sexual decision-making power, pressures to form sexual relationships at a young age, and associations of condom use with lack of trust and promiscuity. Therefore, women's lack of control over the sexual lives of their partners and the inability of women to insist on condom usage makes them particularly susceptible to HIV infection and AIDS.

As the number of new cases of HIV infection continues to escalate in especially disadvantaged women, treatment modalities for symptomatic HIV or AIDS are not sufficient. Kalichman et al. (2002) stated that antiretroviral treatment (ART) was mainly available in the most developed countries. Their research as well as previous research studies found that minorities, women and persons with lower education levels or of lower socio-economic status were less likely to be treated for HIV/AIDS than were whites and persons with higher education levels, respectively. According to Withell (2000), AIDS in the West had over time come to be considered a chronic, more manageable disease. She

stated that this belief was disturbing when universal epidemiological figures of HIV infection continued to rise at a shocking rate among the disadvantaged in developing countries, who had little or no hope of receiving treatment to prolong life or ameliorate suffering.

Nevertheless, the '3 by 5' initiative of the UNAIDS (United Nations Programme on HIV/AIDS), WHO (World Health Organisation) and other international organisations, launched in 2003, has increased the number of disadvantaged people receiving antiretroviral (ARV) therapy (UNAIDS, 2005). The goal of the initiative is to provide ARV therapy to 3 million people in developing and transitional countries by 2005. According to the UNAIDS report on AIDS in Africa (2005) the upward trend in ARV provision was particularly evident in sub-Saharan countries, where the number of people receiving ARV therapy had doubled to 325 000 by December 2004. ARV therapy coverage in this region was estimated at 8%. Despite this increase there were still 4 million HIV-infected people in need of treatment in sub-Saharan countries. To reach the '3 by 5' initiative's target of 3 million people by the end of 2005 requires having at least another 2.3 million people starting treatment. According to the UNAIDS report (2005) a total of 5.1 million adults still need treatment in 2005 and are not receiving it; 72% live in sub-Saharan Africa and 22% in Asia. South Africa, India and Nigeria together accounted for 41% of the unmet need.

In South Africa, the majority of people from disadvantaged groups and low-income women with HIV/AIDS have up to now not received adequate medical care and antiretroviral treatment (ART) for their illness. Although the government has embarked on a national programme to provide ART to all South Africans in need and who meet the criteria for eligibility, by September 2004 just over 11 000 South Africans had been placed on treatment since the programme started in April 2004 (Brouard, 2005). According to estimates, approximately 500 000 South Africans were in need of ART in 2004. The target announced by President Mbeki of 53 000 people on treatment by March 2005 was thus not reached. This means that the majority of HIV-infected low-income women in South Africa still have to cope with the progression of a devastating illness, as well as accompanying

stressors, without treatment and adequate support. The delay in providing antiretroviral drugs to HIV/AIDS patients could cause confusion, loss of dignity, suffering and death.

The National Burden of Disease (BoD) Study, the first ever national BoD study carried out in South Africa, attempted to arrive at coherent and consistent estimates of the BoD experienced in South Africa in the year 2000 (Bradshaw et al., 2003). The study found that HIV/AIDS was the leading cause of all deaths (30%), and accounted for 34% of female deaths and 26% of male deaths. Examination of age distribution showed that it was particularly young, female adults who are dying of AIDS (Bradshaw et al., 2003).

In South Africa, most low-income pregnant women do not have the basic right to decide whether they want ART treatment, which could prevent their babies from getting infected with HIV, as well as prolong their own lives. The Head of the Medical Research Council stated, "The decision not to use antiretroviral drugs for the prevention of mother to child transmission of HIV poses a serious moral and ethical dilemma in a nation where maternal-foetal transmission accounts for 10% of the total HIV disease burden" (cited in Mkosi, 2000, p.35).

Benefit from treatment is contingent upon early diagnosis and access to HIV-care services. Sarna et al. (1999) pointed out that in the early phases of the HIV epidemic, few women were diagnosed, and information about disease presentation in women was partial. Even at present, the lack of data about women with HIV/AIDS can cause women to be misdiagnosed, or can lead to a delay in diagnosis. Gaskins (1999), Haigney (cited in Cohan & Atwood, 1994) and Stevens (cited in Sarna et al., 1999) stated that late HIV diagnoses resulted in women obtaining medical intervention and care at later stages during the progression of the illness, and therefore they were sicker than men when they begun with treatment. Schoenbaum & Webber (2000) and Sowell et al. (1999) emphasised that there was data to show that women with HIV/AIDS first presented for medical care with more advanced symptoms that rapidly progressed, and had a shorter survival time than their male counterparts. Hankins (cited in Heath & Rodway, 1999) pointed out that if women with HIV/AIDS had access to needed healthcare, their rate of disease progression

would not be worse than that of men. Therefore, the difficulties women with HIV/AIDS, particularly impoverished women, experience with finding prompt and appropriate healthcare may affect their overall health status and their quality and duration of life (Cu-Uvin et al., cited in Sarna et al., 1999).

Furthermore, women's psychological response to HIV infection, including the trauma of a positive diagnosis, may have implications for disease progression and survival (Earl et al., cited in Kaplan, Marks & Mertens, 1997). Burach (cited in Rose & Clark-Alexander, 1996) and Kaplan et al. (1997) discussed an emerging body of literature in psychoneuro-immunology which suggested that psychosocial phenomena such as depressed mood, hopelessness and fatalism, anxiety and loneliness might accelerate the pace at which HIV progresses. Consequently, a major focus of care for women with HIV/AIDS should be on the psychosocial facets of the illness and not only on the physical treatment of illness symptoms.

1.3 The psychosocial impact of HIV/AIDS on women

In the literature it is emphasised that besides medical treatment and physical care, women in particular have specific psychosocial needs in relation to HIV/AIDS because of their often disadvantaged position in society and their caregiving roles. Kalichman et al. (2002) argued that although medical treatment and symptom management are of the utmost importance for women with HIV/AIDS, interventions focusing only on one aspect of the HIV/AIDS experience have limited usefulness. According to these writers emotional, social and spiritual issues can enhance or hamper the physical management of the disease, just as physical well-being can influence psychosocial functioning. Sowell et al. (1999) explained that during the various stages of the disease, issues relating to psychological, social and spiritual needs are apparent, and during periods when symptoms are not present or manageable, these factors may actually be of greater importance than the physical health issues associated with the disease.

Researchers have described AIDS as a chronic, unpredictable, life-threatening illness in which suffering is exacerbated by bereavement, stigma, poverty and other coexisting stresses (Catz et al., 2002; Withell, 2000). Because HIV/AIDS is an extremely complex illness process it affects all aspects of an individual's life. HIV/AIDS not only threatens physical and mental health but every aspect of a person's existence, from primary relationships to economic survival (Stein, Steinberg, Allwood, Karstaed & Brouard, 1994; Walker, Pomeroy, McNeil & Franklin, 1996).

In the literature it is clear that stigmatisation and blaming often mark the HIV/AIDS discourses in Africa (Grinstead, Gregorich, Choi & Coates, 2001; Haram, 2001; Leclerc-Madlala, 2001; Morrow, Costello & Boland, 2001; Rabinowitz & Canale, 2004; Withell, 2000). Stigma sets HIV/AIDS apart from other terminal illnesses and the disease is defined as a "mark of shame or discredit" for the reason that it is often associated with unacceptable lifestyles and activities such as prostitution, indiscriminative sex with multiple partners, and loose morals (Heath & Rodway, 1999, p.45). Many researchers have found that the disclosure of an HIV-diagnosis raises crucial issues regarding stigma, discrimination, isolation, alienation, reduction in self-esteem and various conflicts and losses arising at different stages of the disease (Dean, 1995; Dicks, 1994; Dukes, 1995; Ewing, 1994; Jue, 1994; Kelly & Lawrence, 1988; Kiemle, 1994; Leask, Elford, Bor, Miller & Johnson, 1997; Macks, 1987; McGinn, 1996; Schurink, 1990; Sewpaul & Mahlalela, 1998). Moneyham et al. (cited in Leenerts & Magilvy, 2000) and Sowell et al. (1999) stated that experiences of stigmatisation affect health outcomes, including mental health and quality of life. Concerns about stigma, revealing one's HIV-status to others and victimisation may disrupt earlier caring and helpful relationships and prevent women with HIV/AIDS from utilising much needed sources of support that could promote effective coping and alleviate psychosocial distress.

Throughout the literature, high levels of psychosocial distress among HIV-infected women have been documented (Broun, 1999; Catz et al., 2002; Sarna et al., 1999; Simoni & Ng, 2000). Broun (1999) argued that although a woman's experiences of being HIV-infected are influenced by her individual psychological make-up, such as premorbid mental health,

sexual orientation, substance abuse, self-esteem, religion and spiritual beliefs, social factors such as socio-economic status and support from important others, family and the community play a prominent role. Withell (2000) stated that in addition to their biological vulnerability to HIV infection, women in developing countries bear a double burden enforced by AIDS because of their subordinate position in society and the heavy burden of their care-providing roles.

Researchers have argued that the difference in distress levels between men and women could be ascribed to disparities in contextual and sociocultural issues, such as poverty, childcare responsibilities, responsibilities for giving care to others infected with HIV, and the differential stigma and social isolation that women living with HIV/AIDS experience (Catz et al., 2002). Leenerts and Magilvy (2000) pointed to recurring themes in the literature concerning the social circumstances of low-income women with HIV/AIDS that may cause psychological distress:

- Worries about daily survival (including care of children), job loss and economic concerns;
- Fears of domestic violence and economic dependence on male partners;
- Social oppression in gender roles and caregiving;
- Poor self-esteem, often attributed to abuse and family dysfunction, manifesting itself in substance abuse;
- Difficulty accessing healthcare resources (problems in getting a diagnosis and receiving quality care);
- Self-neglect, self-sacrifice, and silence;
- Homelessness, welfare bureaucracy, and lack of health insurance and care. (Berer et al. and Rudd et al., cited in Leenerts & Magilvy, 2000, p.69)

According to Hackl, Somlai, Kelly & Kalichman (1997) and Tallis (1998), the psychosocial strains on HIV-infected women and mothers with few financial resources are often compounded by the multidimensional responsibilities of being the family's primary caregiver. Pienaar (2003) pointed out that low-income women's access to treatment and care also proves to be more restricted than men's since women expend available resources

on children and the household, before attending to their own health needs. Williams (1995) stated that many low-income women with HIV are socially isolated from support services by factors such as unemployment, being single mothers, lack of convenient transportation, and substance abuse. Furthermore, public health services are generally fragmented, hospital based, and not culturally appropriate, and therefore low-income women are the most underserved HIV/AIDS-infected population of all. It is clear that AIDS is only one crisis among many that low-income women must deal with.

Women with HIV/AIDS generally experience a wide range of social, emotional and psychiatric problems that are accompanied by numerous personal and social losses (Martinez et al., 2002). Catz et al. (2002) and Heath and Rodway (1999) pointed out that frequent themes in the literature concerning the psychological impact of HIV infection on women are feelings of betrayal, failure, insufficiency, guilt and shame, anxiety, depression, anger, low self-esteem, uncertainty about the course of the illness, fear of rejection, fear of death, feelings of loss of power and control, and suicidal ideation. Withell (2000) identified bereavements, social losses (especially those associated with widowhood as well as being rejected by family and friends), loneliness, poor self-esteem, sexual limitations, and loss of direction (future plans) as important personal and social losses. Depression, anxiety, and loneliness were often found to be the most common and distressing psychological reactions following a diagnosis of HIV or AIDS (Catz et al., 2002; Faithfull, 1997; Gillman & Newman, 1996; Jue, 1994; Kaplan et al., 1997; Kiemle, 1994; Linn, Poku, Cain, Holzapfel & Crawford, 1995).

The psychosocial impact of HIV/AIDS can vary at different stages of the illness. According to Stevens et al. (cited in Withell, 2000), the initial impact of an HIV-diagnosis is commonly characterised by shock, disbelief, fear and numbness, and feelings of devastation may progress to suicidal thoughts. According to Heath and Rodway (1999), some writers describe certain feelings as being more prevalent at different times in the illness process, such as shock at the time of diagnosis and spiritual/existential issues at a later phase. Other writers stated that some women face spiritual/existential issues immediately after

diagnosis because of the connection between AIDS and premature death (Christ et al., cited in Heath & Rodway, 1999).

It can be argued then that HIV/AIDS has a particular psychosocial impact on low-income women. Consequently, issues such as stigma, disclosure and physical and mental healthcare and social circumstances such as poverty and domestic abuse should be treated as special concerns, problems and challenges by healthcare-providers (Withell, 2000). Gaskins (1999) stated that stigma urgently needs to be addressed in HIV/AIDS care for women because of its detrimental influence on emotional distress, on how women manage their illness and personal healthcare, and on their quality of life in general.

In the literature it is clear that physical illness symptoms/conditions caused by the HIV infection itself or by related opportunistic infections, as well as the psychosocial distress experienced by women with HIV/AIDS, have a detrimental effect on their general well-being and functioning. The need for the provision of comprehensive and more effective medical, social and mental healthcare for disadvantaged and poor women/mothers with HIV/AIDS from different cultures has been frequently emphasised (Goosen & Klugman, 1996; Kalichman et al., 2002; Linn et al., 1995; Littrell, 1996; Mapekula, 1996; Van Coeverden de Groot, 1997; Williams, 1995). Because disadvantaged or poor women generally do not receive the treatment and care they need, they could fall ill more rapidly and this could lead to early death. Research has also found that physical distress and pain are associated with psychosocial distress and a decline in psychosocial functioning. Therefore, integrated approaches to HIV treatment that provides quality medical and mental healthcare as well as social support for women living with HIV/AIDS should be the focus of healthcare providers.

1.4 Neglect of women in HIV/AIDS research

Although research studies on women with HIV/AIDS are on the increase, the illness has been seen predominantly as an illness of men and research studies describing the

experiences of women have been generally neglected (Dicks, 1994; Faithfull, 1997; Kaplan, 1995; Land, 1994; Norman & Dumois, 1995; Sarna et al., 1999; Simoni & Ng, 2000; Strebel, 1995; Treichler, 1999; Williams, 1995).

Treichler (1999) stated that despite documented cases of AIDS in women from almost the beginning of the epidemic, AIDS was assumed by most of the medical and scientific community to be a "gay disease" and a "male disease", considered to be different from other sexually transmitted diseases. Women have since then primarily been studied in a discriminatory way as sources of infection via mother-child transmission, intravenous drug use and prostitution (Withell, 2000).

According to Treichler (1999), most studies of women with HIV/AIDS were explicitly justified by arguing that HIV incidence in women provided a general index to the heterosexual spread of the virus and that the purpose of identifying women at risk and preventing primary infection in them was to prevent cases of HIV/AIDS in their partners and children. Cohan and Atwood (1994) stated that when the issue of women and AIDS was addressed, perinatal studies and concerns for the well-being of foetuses typically obscured the social and healthcare needs of infected women. Consequently, there was no inherent concern for women as women, because discussion seemed to remain limited to how women could prevent infecting others.

The growing incidence of HIV/AIDS among minority and low-income women and the detrimental impact it has on their lives make it important to understand how the illness process affects these individuals. Catz et al. (2002) found women's psychological well-being or the lack thereof (psychological distress) to be an issue of particular importance. In the literature it is clear that higher levels of psychological distress have an adverse influence on quality of life and have been linked to poor treatment adherence and self-care, and higher risk behaviour for HIV transmission among women who are living with HIV/AIDS (Catz et al., 2002). Therefore, research studies should focus to a greater extent on poor minority and disadvantaged women in general, who in most cases do not have access to appropriate and needed medical treatment, healthcare and psychosocial support.

In South Africa, the majority of research studies and projects on HIV/AIDS have focused mainly on awareness, risk factors, prevention and attitudes towards AIDS in general. According to Kelly and Parker (2001), most research has not been designed to develop theoretical frameworks for understanding the effect of HIV/AIDS on women or tools for intervention. They stated further that there has been particularly a lack of research on social mobilisation, integration of services, service delivery and other crucial issues which impact on prevention and care efforts for people with HIV/AIDS. Moreover, much of the social science research has focused on specific behavioural outcomes, rather than on data gathering about social support, care and intervention that could benefit women with HIV/AIDS.

South African studies that have focused on the psychosocial impact of HIV/AIDS on women are the following:

- Berman's (1993) ecosystemic analysis of the skills of women to cope with HIV/AIDS;
- Lindegger's (1993) report on "AIDS and women, an investigation of psychological issues in women's self-protection against HIV/AIDS";
- Karim's (1993) study of "Women and AIDS in Kwazulu-Natal: determinants of the adoption of HIV protection";
- Strebel's (1993) study of "Women and AIDS and issues in the prevention of HIV infection";
- Tallis's (1997) exploratory investigation into the psychological impact of an HIV-positive diagnosis in a small sample of pregnant women in Kwazulu-Natal;
- Sewpaul and Mahlalela's (1998) study that explored the psychosocial issues and concerns of young HIV-infected mothers in Kwazulu-Natal, titled "The power of the small group: from crisis to disclosure";
- Mfusi and Mahabeer's (2000) study regarding the psychosocial adjustment of pregnant women infected with HIV/AIDS in South Africa;
- A report by the South African Directorate of Communication, Department of Agriculture and Department of Health, Pretoria, (2001) on "HIV/AIDS and the farming community: what women should know";

- De Villiers Herbst's (2001) study of "The loneliness of HIV-infected low-income mothers: implications for health workers";
- Vetten and Bhana's (2001) preliminary investigation into the links between violence against women and HIV/AIDS in South Africa;
- Nieuwmeyer's (2002) study of Xhosa-speaking African women living with HIV and women grieving over the death of loved ones as a result of AIDS;
- Raganya's (2003) research paper titled "To tell or not to tell: social support, coping and depression after disclosure of women's HIV-positive status";
- Phiri, Haddad and Masenya's (2003) study on African women, HIV/AIDS, and faith communities;
- Ahmed's (2003) analysis of Muslim AIDS activism in relation to women living with HIV/AIDS in Cape Town;
- Pienaar's (2003) study of "The untold stories of women in historically disadvantaged communities, infected and/or affected by HIV/AIDS, about care and/or the lack of care";
- Parson's (2003) historical review of the prevention of mother-to-child HIV transmission in South Africa;
- Smyth's (2004) phenomenological inquiry into the lived experience of social support for Black South African women living with HIV;
- Zuyderduin's (2004) analysis of the Buddy system of care and support for and by women living with HIV/AIDS in Botswana;
- Mashao's (2004) study of the empowerment of women through the integration of HIV/AIDS issues and literacy at community level.

The above studies indicate that the psychosocial impact of HIV/AIDS on South African women has been receiving more attention in research agendas. However, considering the risk factors and high prevalence of HIV/AIDS in women there still exists a great need for research studies focusing primarily on how women, especially poor minority and disadvantaged women of colour, experience being HIV-positive, and how these women actually live and cope with their diagnosis. Furthermore, no research studies on minority groups, such as the Coloured women in the Western Cape, exploring these issues have been reported. Consequently, there is an urgent need for research studies in South Africa

to explore the range of discourses revealed by low-income and minority women regarding their lives and experiences of HIV/AIDS, in order to generate understanding and knowledge which could contribute to possible interventions, support and care.

1.5 Neglect of social context in HIV/AIDS research

Sowell et al. (1999) emphasised that HIV/AIDS, like any other disease, does not occur in isolation or beyond the context of an individual's life experience. The lived experience of HIV/AIDS affects the process and outcome of the illness. These writers argued that it is impossible for women with HIV/AIDS to consider the impact of the illness on their lives separate from such social factors as poverty, discrimination, gender role expectations, gender inequalities, crime and violence. Women most frequently diagnosed with HIV/AIDS are poor and underprivileged women who are prone to persistent poverty circumstances and are not likely to have the personal and healthcare treatment opportunities required to effectively manage the disease (Brady, Gallagher, Berger & Vega, 2002; Richardson, Barkan, Cohen, Back, FitzGerald, Feldman, Young & Palacio, 2001; Sowell et al., 1999). Olley, Gxamza, Seedat, Stein and Reuter (2003) stated that in South Africa, women with HIV/AIDS may be at greater risk for psychopathology than patients in certain parts of the developed world, given the additional factors of their potentially stressful living conditions which include high levels of unemployment and poverty; poor and unstable housing; inadequate social services; and high rates of crime and domestic abuse.

According to Gillman and Newman (1996) and Hackl et al. (1997) there is insufficient knowledge about the special needs and concerns of HIV-infected women/mothers from different cultures with regard to their healthcare, children, partners, financial status and sense of future. Kaplan (cited in Schneider; 1992) stated that psychosocial dimensions that have an impact on stress, such as family responsibilities, coping strategies, role strain, life events and social support, are theoretically constructed differently for different cultural groups. Bradshaw et al. (2003) emphasised that efforts to improve health and healthcare in South Africa would have to extend to the very core of our society and cultures because

health problems are socially and culturally rooted. Thus, to provide needed and adequate healthcare for women with HIV/AIDS from different cultures, such as the Coloured women in the Western Cape, knowledge must be gained about their specific problems, stressors and needs regarding their illness, as well as their life circumstances and living conditions.

Kelly and Parker (2001) advocated contextual HIV/AIDS research, which needs to be guided by simple tools for contextual analysis that opens pathways for mobilisation of local health-giving and problem-solving action. According to Gow, Jubber, Marcus and Richter (2001), adequate social understanding requires in-depth first-hand information. These writers referred to the study done by Leclerc-Madlala (2001) through which she provided useful insights into her subjects' views and behaviours, but also showed how day-to-day behaviour in relation to HIV/AIDS is structured by deep-seated cultural assumptions and views. Gow et al. (2002) emphasised that ideas about HIV/AIDS have to be worked into culturally deep-rooted views about femininity, sexuality, family, illness and ill fortune.

Although there is a paucity of South African research studies concerning women and HIV/AIDS, the studies that have been conducted have focused primarily on women in Black communities. Consequently, in-depth qualitative studies that also explore the experiences of women with HIV/AIDS from other cultures, and specific regions, such as the Coloured women in the Western Cape, are necessary for the planning of appropriate and efficient interventions, healthcare and support services for all women in need.

1.6 Conclusion

In South Africa, disadvantaged and poor women are traditionally the most marginalised and oppressed sector of our society and are now facing the added burden and devastating effects of HIV/AIDS. Despite the urgency and the scope of this problem, little is known about how this marginalised population experiences being HIV-positive. As a result, services are often inadequate and fail to address the psychosocial needs and concerns of these women. To plan and offer appropriate and needed psychosocial services and to improve

and rectify existing services in South Africa, in-depth qualitative research studies focusing on the experiences of low-income women within their specific sociocultural contexts are imperative.

The present study is an endeavour to enhance our understanding of HIV-infected Coloured women living in the Winelands region of the Western Cape. These women form part of a poor and minority cultural group in South Africa, among whom the numbers of new HIV infections and AIDS cases are continuing to rise. The study thus aims to:

1. Explore the psychosocial concerns and mental health needs of HIV-infected low-income Coloured mothers in everyday life;
2. Construct a testable Grounded Theory regarding the illness experience of low-income Coloured mothers;
3. Recommend guidelines for health workers.

As such, it is also hoped that this study serves as a documentation of the illness experiences of one particular group of women in South Africa.

In a previous research paper titled "The loneliness of HIV-infected low-income mothers: implications for health workers", the focus was on loneliness, as a primary psychological concern for the participants of this study, as well as on the mental health needs that emanated from this concern (De Villiers Herbst, 2001). This assignment was presented in partial fulfilment of the requirements for the degree of Master of Arts (Clinical Psychology) at the University of Stellenbosch. However, the present and more comprehensive research document includes loneliness as an important psychological concern, but yields additional and extended data regarding physical symptoms and distress, and other critical social and psychological concerns, distress and mental health needs experienced by the participants in this study. Therefore, the voices/narratives of the participants are documented, so that the reader may develop an understanding of how these women experienced their illness within their specific sociocultural context.

1.7 Organisation of the dissertation

In Chapter 2, social constructionism as theoretical point of departure and framework for this study is discussed. In Chapter 3, theoretical perspectives on illness, health, women and AIDS are presented. The research methodology of the study is explained in Chapter 4. In Chapter 5, the Grounded Theory analysis of the qualitative data is presented and discussed. Lastly, a summary of findings, a critical review of the study, and recommendations are provided in Chapter 6.

In the present study research data were analysed according to Constructionist Grounded Theory (Chapter 4) that aims to develop new, contextualised theories. According to Grounded Theory protocol, the relevant literature on HIV/AIDS and women was consulted for comparison after the researcher had developed the conceptual analysis of the data. Thus, significant literature and research are cited, discussed, and compared with the analysis of the present study in Chapter 5. However, a brief review of the psychological literature on the illness experience of HIV-infected women in the field of Psychology is presented as Addendum A (p.313).

CHAPTER 2

Social constructionism: a theoretical framework for this study

> *Although all human beings experience the universal physical phenomena of birth, growth, illness, aging, and death, and each individual's experiences of these phenomena is particular, between these universals and these particulars are the similarities that come out of membership in social groups – women and men of various racial categories, ethnicities, and economic classes living at different times and in different places. Their social location produces their patterns of health and illness behaviour, with the actions of professionals they encounter in seeking help and the organizational structure of the medical system they must deal with in getting treatment are equally important in shaping their experiences as patients. (Lorber, 1997, p.7)*

2.1 Defining social constructionism

The recent interest in constructionism reflects the rising scepticism about the positivist tradition in science and essentialist theories of truth and meaning (Rorty, cited in Hare-Mustin & Marecek, 1990). Essentialism relies on a concept of true essences, with an assumption (found in positivism) that we can know these true essences directly and objectively (DeLamater & Hyde, 1998). Social constructionism disputes this belief by hypothesising that we cannot know anything about true essences or reality directly, but rather that people at all times engage in socially constructing reality. Greenwood (1992), Gonzalez, Biever and Gardner (1994) and Hare-Mustin and Marecek (1990) emphasised that social constructionism disputes the idea of a single meaning of reality and a single truth. Rather than searching for "the truth", social constructionism highlights the ways in which meaning is negotiated, the way in which those in power often determine meaning, and how meaning is represented in language (Hare-Mustin & Marecek, 1990).

Social-constructionists argue that the social context shapes knowledge, and that meaning is historically placed and constructed and reconstructed through the medium of language.

Gergen (cited in Wick, 1996) stated, “The terms in which the world is understood are social artefacts, products of historically situated interchanges among people” (p.66). According to Wick (1996), this is a direct challenge to the traditional scientific thinking that views the knowledge about our world as “discovered”. Furthermore, it questions the fundamental assumption of the separation of the subject-object relationship between the knower and the known (Wick, 1996).

Constructionism also challenges the presumption of positivist science that it is possible to differentiate facts from values. For constructionists, values and attitudes determine what are taken to be facts (Howard, cited in Hare-Mustin & Marecek, 1990). It is not that formal laws and theories in psychology are wrong or worthless, rather, as Kuhn (cited in Hare-Mustin & Marecek, 1990) affirmed, they are explanations based on a set of agreed-on social conventions. “Whereas positivism asks what are the facts, constructionism asks what are the assumptions; whereas positivism asks what are the answers, constructionism asks what are the questions” (Hare-Mustin & Marecek, 1990, p.28).

According to Scarr (cited in Gonzalez et al., 1994), we do not discover scientific facts; we create them. Their value to us depends both on shared perceptions of the “facts” (consensual validation) and on whether they work for various purposes, some practical and some theoretical (Scar, cited in Gonzalez et al., 1994). The focus is therefore on how and when a theory is useful rather than on attempting to confirm or refute theoretical ideas.

The positivist tradition holds that science is the paradigm of the right use of reason, neutral in its methods, and socially advantageous in its results (Flax, cited in Hare-Mustin & Marecek, 1990). Constructionism holds that scientific knowledge, like all other knowledge, cannot be disinterested or politically neutral. Lupton (1995) stated that constructionism is fundamentally an approach which questions claims to the existence of essential truths:

> What is asserted to be “truth” should be considered the product of power relations, and as such, is never neutral, but always acting in the interest of someone. The poststructuralist perspective argues therefore that all knowledges are inevitably the products of social relations, and are subject to change rather than fixed. (p.11)

Thus, from a constructivist perspective theories of illness and health, like all scientific theories, are representations of reality that are organised within specific assumptive frameworks and that reflect certain interests.

DeLamater et al. (1998) summarised the constructionist paradigm around five statements based on the writings of Berger and Luckmann in *The social construction of reality*:

1. People's experience of the world is ordered. We observe the world as comprised of discrete events and specific persons engaging in distinct actions in a specific order. We experience the world as an objective reality, made up of events and persons that exist independently of our view of them.
2. We make sense of the world through the use of language. Language endows us with the categories that we use to classify events and persons and to order them. It also provides the means by which we interpret and understand new experiences.
3. The reality of daily life is shared. Other people perceive reality in much the same way as ourselves, as consisting of comparable events, persons, actions, and order. This shared nature distinguishes the reality of everyday life from distinctive realities, such as our dreams. Language enables us to share experiences, knowledge and feelings with others. Therefore reality is a product of social interaction (Gergen, cited in DeLamater et al., 1998).
4. Shared categories of reality become institutionalised. Shared typifications of people and events cause habitualisation, which makes the behaviour of others predictable, facilitating cooperative activity (Mead, cited in DeLamater et al., 1998). Once a typification or practice becomes customary, others come to expect it, and methods of social control are developed to be responsible for it.
5. Knowledge may be institutionalised at the level of society, or within subgroups. A subconstruction of meaning is a socially segregated store of knowledge contained and accepted by a specific group of people (DeLamater et al., 1998, p.14).

The description of social constructionism shows that it is much more than just resistance and opposition to the scientific tradition of positivism. In the literature it is described as an active and subjective approach of becoming involved with how people make meaning of

their lives. It is also depicted as an orientation that confirms values and understands the many ways that different people make meaning of their lives in their various contexts (Lesch, 2000).

2.2 Constructing reality

Central to social constructionism is the assumption that reality is socially constructed. Hare-Mustin and Marecek (1990) emphasised that, rather than passively observing reality, we actively construct the meanings that frame and organise our awareness, perceptions and experience of reality. Thus, our understanding of reality is a representation, not a precise replica, of what is "out there". According to Hare-Mustin and Marecek (1990), representations of reality are shared meanings that are gained from shared language, history, and culture. Therefore constructionism challenges the scientific tradition of positivism, which holds that reality is fixed and can be observed directly, uninfluenced by the observer (Segal, cited in Hare-Mustin & Marecek, 1990). As Heisenberg (cited in Hare-Mustin & Marecek, 1990) pointed out, a truly objective world, devoid of all subjectivity, would have no one to observe it.

Berger and Luckman's influential work *The social construction of reality* (1967), originating in a phenomenological analysis, had immediate importance throughout the social sciences (cited in DeLamater et al., 1998). For these writers the commonsense reality of everyday life occupied a privileged position among the multiple realities of experiencing the world. According to Berger and Luckman (cited in Treichler, 1999), this reality of everyday life offers a domain where our subjective experience of the world seems truthful and meanings seem to be shared with others without difficulty. Thus, according to them, the purpose of sociological analysis is analysis of the self as it goes about creating meaning in everyday life. Treichler (1999) stated that the book's very title, its insistence on the validity of multiple socially constructed realities, and its analysis of ideology's role in deploying what we think we know to resolve knowledge that has been rendered problematic, encouraged a new way of thinking about the production of knowledge. This approach was different

from the pervasive realism and absolute determinism of post-war social science. Treichler (1999) emphasised that reality is always contextual, always to be read and understood in relation to specific discourse practices, specific metaphors, and the representations and claims in which a specific discipline or subdiscipline specialises. Treichler (1999) maintained that the concept of cultural construction could be understood as follows:

> It is a way of talking about how knowledge is produced and sustained within specific contexts, discourses, and cultural communities; it takes for granted metaphor and other forms of linguistic representation; it presupposes that ideas are produced out of concrete contexts and have concrete effects; it takes for granted hermeneutical activity; it is a complex of ideas and operations sustained over time within a given community; hence, it is institutionalized. (p.173)

Treichler (1999) declared that although frequently confused with idealism or more lately with a view that "everything is discourse", the conception of cultural construction is not a matter of arbitrarily visualising an enigmatic material reality but one of engaging in highly non-arbitrary ways with the material world. Treichler (1999) argued that even if meaning is subjective and fluid, it does not mean that it is arbitrary and fluid within a given signifying system. She emphasised that the predictability and stability provided by a given history, society, culture, and set of disciplinary conventions are anything but arbitrary. She further argued that this point is often misunderstood when a given meaning or idea is termed a cultural construction:

> Within the signifying system, that **is** the meaning. No wonder then, that we expend great effort to preserve belief in a given system where meaning appears stable, indeed, even universal. Recognition that reality is culturally constructed makes such belief impossible. (Treichler, 1999, p.173)

Gonzalez et al. (1994) also stated that social constructionism declares that meanings and understandings are fluid and always changing. Furthermore, as social interactions are performed mainly through dialogue, language is considered to be the key medium for the transmission of meanings and understandings.

2.3 Social constructionism and language

Constructionists regard reality as socially co-created through communication between or among people. According to Wick (1996), the commonly accepted basic foundation of this reality is language, the spoken or written word. Anderson et al. (cited in Wick, 1996) stated, "Human systems are language-generating, and simultaneously, meaning-generating systems... Hence, any human system is a linguistic of a communicative system... In the domain of meaning, social systems are communication networks that are distinguished in and by language" (p.74).

Lupton (1995) stated that the poststructuralist concept of discourse links up with the structuralist semiotic analysis of language and the way that meaning is created with an understanding that language does not exist in a social void, but is steadfastly grounded in a social, cultural and political background and used for specific ends. Thus, from a poststructuralist perspective, subjectivity is discursively created through language in specific historical and cultural contexts (Miles, 1995). Miles (1995) further explained that in poststructuralist theory, the subject is constituted within language, rather than existing as an "author of meanings" prior to language. Individuals therefore become positioned in discourses and these work to create their subjectivity. According to Haug (cited in Miles, 1995), positioning in particular discourses is influenced by an individual's particular life history, but the range of possibilities is socially determined. Lupton (1995) described discourse in this usage as follows:

> A pattern of words, figures of speech, concepts, values and symbols. A discourse is a coherent way of describing and categorizing the social and physical worlds. Discourses gather around an object, person, social group or event of interest, providing a means of "making sense" of that object, person, and so on. (p.18)

Lupton (1995) stated that any communication that is verbal is considered a text worthy of attention for the identification and description of discourses. Therefore the examination of texts is the focus and core of discourse analysis and other forms of interpretive and

descriptive research (Lupton, 1995). Brandt (cited in Lupton, 1995) argued that when applied to sociocultural analyses of medicine; the analysis of discourse could demonstrate "the process by which biology and culture interact" in the social construction of disease, and the manner in which western culture uses disease to describe social boundaries (p.19). The analysis of discourse can therefore also show how language is used to establish power relations within these social structures.

2.4 Social constructionism, power and discourse

From a social-constructionist perspective it is argued that discourse is ingrained in relations of power. According to Danziger (1997), current patterns of interaction are dependent on power structures created in the past and upheld by many institutionalised practices and conventions. Therefore, power plays an important role in everyday social and interpersonal relations (Meyer, 1996).

Hare-Mustin and Marecek (1990) pointed out that the relation between meaning and power has been a prime focus of postmodernist thinkers such as Foucault. Their inquiry into meaning focuses mainly on language as the medium of cognitive life and communication. Therefore language is seen not simply as a mirror of reality or a neutral tool (Wittgenstein, cited in Hare-Mustin & Marecek, 1990). As Bruner (cited in Hare-Mustin & Marecek, 1990) stated, "language imposes a point of view not only about the world to which it refers but toward the use of the mind in respect to this world" (p.25). Hare-Mustin and Marecek (1990) further emphasised that language unavoidably structures one's own experience of reality as well as the experience of those to whom one communicates: "just as in any interaction we cannot 'not communicate', so at some level we are always influencing one another and ourselves through language" (p.25). Consequently, meaning-making and control over language are vital resources held by those in power and, like other valuable resources, they are not distributed fairly across the social hierarchy (Hare-Mustin & Marecek, 1990). Barthes (cited in Hare-Mustin & Marecek, 1990) described language as a sign system used by the powerful to label, define, and rank.

Foucault's work has been invaluable in focusing attention on the way language is organised around different systems of meaning which offer positions of power to certain categories of people and disempower others (Parker, Georgaca, Harper, McLaughlin & Stowell-Smith, 1995). Hare-Mustin and Marecek (1990) emphasised that throughout history, men's influence and power over language has been greater than that of women. These writers explained that men's dominance in academic institutions, inter alia the medical field, has influenced the social production of knowledge, including the concepts and terms in which people think about the world. According to Parker et al. (1995), in current debates in psychology, critical writers studying structures of power in discourse are emphasising what oppressed people have long been aware of, that the way health professionals generally talk is bound up with privilege and, at times, hostility. Danziger (1997) argued that institutionalised power structures in the medical realm can be perceived as a given that pervades the daily lives of individuals, such as disadvantaged women, which in turn determines their illness experiences.

According to Bury (in Lupton, 1995), there is a range of political views regarding power and power relations within the field of illness and health that are taken by scholars adopting the social-constructionist approach. Lupton (1995) stated that some view medical knowledge as neutral, while others give emphasis to the social-control function of discourses, arguing that such knowledge and its accompanying practices strengthen the position of powerful interests to the exclusion of others. The latest disposition for those embracing the social-constructionist perspective is to argue that medical power not only resides in institutions or privileged individuals, but is positioned by every person by way of socialisation to accept certain values and norms of behaviour (Lupton, 1995). This viewpoint links up with the Foucauldian perspective that power is not owned by particular social groups like medical professionals, but is relational, a strategy which is invested in and transmitted through all social groups.

From a feminist perspective, Greenspan (1993) argued that the medical model encourages women to find individual solutions to many health problems that may not best be solved

individually. As a result, women are discouraged from finding more social or collective ways of empowering themselves to solve problems regarding their health. According to Unger and Crawford (1996), we cannot observe individual behaviour in isolation from sociocultural circumstances and the power relations within these circumstances, given that psychological as well as bodily symptomology is strongly tied to what normative roles are obtainable. Thus, social constructionism compels us to look at the situational context of women's lives and helps us understand women's experiences of illness and health within specific power structures.

Bohan (1993) also emphasised that social constructionism discloses the real concerns and problems of power for women, by transferring the focus from the individual to the context of the individual. This opens the way for new interventions to achieve power equality for women, because the focal point is the social context rather than the individual. Therefore the most important question is, what contextual changes would facilitate the empowerment of women, rather than what women should do to obtain power (Lesch, 2000). Weis (1998) argued that although power has a significant social-structure component, it also has important interpersonal components. Therefore the diminution of the concept of power to only its structural foundation oversimplifies the complexity of power in relationships (Weis, 1998). It is acknowledged that power can be defined as the net ability to bring about intended outcomes in a relationship, mostly to influence another person's behaviour toward that outcome. Thus, social-structure factors like social status and access to opportunities as well as interpersonal issues like personal skills, knowledge and competence play a vital role in shaping power (Lesch, 2000).

From a social-constructionist perspective, power balances have an influence on all spheres of human functioning, including intrapersonal, interpersonal and macro structural levels (Lesch, 2000). In accordance with social-constructionist theory, in this study an attempt will be made to take into account all three levels of human functioning.

2.5 A critical look at social constructionism

In this section some of the disadvantages and advantages of social constructionism will be discussed. It is evident in the literature that different critics interpret social constructionism in different ways. Therefore it is problematic to put forth a thorough and coherent critique of social constructionism.

2.5.1 Disadvantages of social constructionism

Lupton (1995) referred to writers such as Turner, Outram and Shilling who criticised constructionist analyses concentrating on medical discourse at the macro-level. According to them broad generalisations are made and detailed examination of the micro-context in which discursive processes take place, such as the everyday experiences of people, are not receiving sufficient attention and focus. These writers, in addition criticised constructionist theory for maintaining that discourses have general social consequences, regardless of social class, gender or ethnicity, and for not recognising human agency and the opportunity for resistance. The critique by these writers opposes the basic assumptions of social constructionism, namely that the meaning of an illness is discursively constructed through language in specific historical, social and cultural contexts. In social constructionism a person's subjective experiences of everyday life within these contexts are of core importance and therefore detailed examination on the micro-level is essential. As stated before in the previous section, power balances within specific social contexts have an influence on all spheres of human functioning, including intrapersonal, interpersonal and macro structural levels.

According to Wrong (cited in DeLamater et al., 1998), social constructionism, with its emphasis on primary socialisation and the learning of language by new members, does not leave much room for individual initiative and originality. The outcome is what Wrong (cited in DeLamater et al., 1998) characterised as an over-socialised conception of the person. He further criticised such conceptions for their failure to recognise the effect of

biology on thought and behaviour. Critics of the social-constructionist approach have furthermore contended that the approach, like all others affected by the poststructuralist movement, can descend into relativism and nihilism. They argued that if this approach is taken to its logical conclusion, that all knowledges are social outcomes, insights of social-constructionist analyses can themselves be disputed (Lupton, 1995). Bury (cited in Lupton, 1995) stated that social-constructionist analyses are themselves contributing to discourses which provide certain ways of observing and understanding the world which are not fundamentally any more rightful or reasonable than other ways. Nicolson and McLaughlin (cited in Lupton, 1995) counter-argued that the intellectual purpose of social constructionism is to emphasise these very dilemmas, and therefore their own analyses should not be regarded as endeavours to define "truth" but as alternative explanations of events which may be placed against other explanations and perspectives for comparison, and judged on their fruitfulness for insight and understanding rather than their plausibility. Lupton (1995), in turn, stated that the social-constructionist approach is not uncompromisingly relativist, because many scholars now emphasise that experiences such as pain and death exist as biological "realities", but such experiences should still be understood through social processes.

Informed by social-constructionist theory, the present research study will focus on the understanding and description of how women construct and experience illness (as a biological and social reality) within their specific social and historical contexts, and not on determining what is true about illness for women in general.

2.5.2 Advantages of social constructionism

According to DeLamater et al. (1998), social-constructionist analyses have several strengths and advantages. Firstly, the fundamental role given to language provides a concrete mechanism by means of which that culture can impact on individual thought and behaviour can be understood. Secondly, social constructionism can symbolise the

complexity within a single culture; it does not assume uniformity. Lastly, it is consistent with variation across societies and over time (DeLamater et al., 1989).

Social constructionism appears to be particularly applicable and significant to research on illness and health. In the literature on illness and health, social constructionism warns against the reductionism of the mainstream theories of illness and health, but also takes account of these theories as providing different perspectives on the illness behaviour of people. Thus, many disciplines have contributed to research on illness and health and several theories can contribute to an understanding of these phenomena. Social constructionism alternatively advocates for a focus on people's experience and understanding of their own illness within their specific social and cultural contexts. It therefore expands the scope of the study of illness and health from a focus on illness behaviours to how people understand and experience those behaviours.

Treichler (1999) stated that the international AIDS narrative is at present neither complete nor fully accessible. She argued that a crisis provides a point of expression for multiple voices and interests, and that the AIDS crisis in the Third World is no different:

1) As in the First World, diverse interests are articulated around AIDS in ways that are socially and culturally localised and specific;
2) Institutional forces and cultural precedents in the First World prevent us from hearing the story of AIDS in the Third World;
3) Understanding this complexity is a necessary, if not sufficient, condition for identifying the material and conceptual nature of the epidemic;
4) Such an identification is necessary in order to effectively mobilize resources and programs in a given country or region. (Treichler, 1999, p.125)

Thus, to be able to hear, understand, and give voice to AIDS narratives in the Third World, it will be vital to identify the concrete and theoretical nature of AIDS in these different countries. Theories and concepts that describe and elucidate how illness is constructed differently in different historical and cultural settings must be pursued (Treichler, 1999). Research conducted within a social-constructionist framework can therefore contribute to

such identification and ultimately contribute to the planning and providing of social- and cultural-context appropriate and effective medical and social support services and programmes for disadvantaged women with HIV/AIDS.

2.6 The implications of a social-constructionist framework for this study

In the literature it is emphasised that the meaning of an illness such as AIDS is discursively constructed through language in specific historical and cultural contexts (Miles, 1995). Treichler (1999) argued that until we understand AIDS's double life as both a material and a linguistic reality, a duality fundamentally part of all linguistic entities but particularly exaggerated and potentially fatal in the case of AIDS, we would not be able to interpret the story of this illness accurately or to plan intelligent and appropriate interventions and treatment programmes. She stated, "We cannot therefore look 'through' language to determine what AIDS 'really' is. Rather, we must explore the site where such determinations really occur and intervene at the point where meaning is created: in language" (Treichler, 1999, p.11). Consequently, AIDS research should be focused on how people make sense of their world and illness experiences within their specific social and cultural contexts.

Nelkin et al. (cited in Cohan & Atwood, 1994) also emphasised that to move towards an understanding of women and AIDS, we must explore the accommodative process between disease and social life in its multiple dimensions, and the languages and images that mediate their interaction. According to Treichler (1999), the observer must get close enough to phenomena to glimpse their true character; "getting a good hard look requires uncovering the rules of everyday practice and attempting to capture the meanings in the culture being observed" (p.158). According to Hare-Mustin and Marecek (1990), when meaning-making through language is concentrated among certain groups in society, the meanings put forth will only be partial, because they exclude the experiences of other social groups. The focus of AIDS research should therefore be to understand how individuals and groups construct and experience HIV/AIDS in different contexts and not to

attempt to determine what is true about the illness for most people in general. New meanings of HIV/AIDS can therefore offer new possibilities for action and thus can foster change in different cultural communities. Therefore the observer must go beyond simply the desire to understand or even to describe the other culture; the researcher must let it speak and then give voice to the story it tells.

The present research study was conducted within a social-constructionist framework where the focus is on how HIV-infected low-income Coloured women make sense of their world and illness experience. Thus, to understand the psychosocial impact of HIV/AIDS on these women, it is essential to focus on how these individual women experience psychological distress, losses and needs in the sociocultural context within which they are functioning. This study is also a systematic analysis and documentation of how the illness (HIV/AIDS) is constructed in narratives of HIV-infected low-income Coloured mothers in the Winelands Region of the Western Cape. The study begins by describing the illness experiences and behaviour of this specific group of women. It further explores how these women make meaning of this experience by looking at their own words in their own language. The researcher attempts to go further than just understanding and describing their experiences; to let these women speak and then attempt to give voice to the stories they tell. There is no hypothesis about a real or universal construction and understanding of HIV/AIDS, thus no generalisations are made on the findings emanating from the data.

The research objectives of the present study were formulated within the framework of a qualitative methodology. Qualitative research methods enhance the rich descriptions of participants and thus the understanding of participants' perceptions and personal experiences within their specific social contexts (Kvale, 1983; McGinn, 1996; Riessman, 1994; Schwandt, 1997; Willig, 2001). Consequently, such detail prohibits the developing of generalisations. Semi-structured in-depth interviewing, the most widely used method of data collection in qualitative research in psychology, was the primary research method used in the present study. Additional data were gained by including questions on socio-demographic and health-related items in the beginning of the interview schedule.

The research design, procedure, and method used to acquire and analyse the data are discussed in Chapter 4. In the following chapter theoretical perspectives on illness, health, women and AIDS are presented.

CHAPTER 3

Theoretical perspectives on illness, health, women and AIDS

The role of a dissident intellectual is not to teach 'theory' to the nontheoretical classes or masses, but to find ways for theories and activisms to learn from each other in the joint effort to re-form the institutions and practices that shape and constrain us all. (Duggan, cited in Treichler, 1999, p.95)

This chapter begins with a general discussion of the meaning of illness and health. Thereafter the medicalisation critique, Foucault's viewpoint on medicalisation and power, and feminist perspectives on the illness experience of women is briefly reviewed. Subsequently the social construction of illness and health, with specific focus on the role of language and power in the social construction of AIDS, is discussed.

3.1 Introduction

Historically, there has been a dichotomy between the ideas of cure and care when examining theories of illness and health. This has been termed "the never-ending oscillation between two different points of view in medicine" (Dubos, cited in Gerhardt, 1995, p.67). Fernández-Ballesteros (2003) pointed out that most definitions of health cluster around one of two views, "namely health as the absence of illness and infirmity (freedom from disease, dysfunction, and disability), or health as a positive state of well-being (a state of equilibrium, adaptation, harmony, and wholeness)" (p.442). According to Gerhardt (1995), these different perspectives have inspired the need to attain balance between the body, the mind and the environment and, against this, the determination to intervene directly in the process of disease. The World Health Organisation (WHO) already declared in 1948 that health is "a complete state of physical, mental and social well-being, and not merely the absence of disease and infirmity" (cited in Fernández-Ballesteros, 2003, p.442). According to Kaplan (cited in Bowling, 1997), the WHO's concept and definition of

health in social, psychological and physical terms has become accepted to the extent that a measure of health status that fails to incorporate one of these dimensions is incomplete and subject to negative evaluation.

According to Fernández-Ballesteros (2003), two supplementary themes that emerged from the many definitions of health are, firstly, that premature mortality is unwanted, and, secondly, that quality of life is essential. Thus, healthcare practices should be concerned not only with evading death but also with the prevention and elimination of conditions that decrease the quality of life of patients. Bruess and Richardson (cited in Fernández-Ballesteros, 2003) explained that health is frequently conceptualised as a multidimensional construct that includes at least six dimensions:

1. Physical health (efficient bodily functioning, resistance to disease, and physical fitness);
2. Mental health (the ability to cope, grow in awareness and consciousness, and grow emotionally and develop to our fullest potential);
3. Emotional health (the ability to control emotions and express them comfortably and appropriately);
4. Social health (good relations with others, a supportive culture, and successful adaptation to the environment);
5. Occupational health (feelings of comfort and accomplishment related to one's daily tasks);
6. Spiritual health (the ability to discover and articulate a personal purpose in life, learn how to experience love, peace, and fulfilment, and how to help oneself and others achieve full potential). (p.442)

Ware (cited in Fernández-Ballesteros, 2003) argued that any comprehensive health appraisal and treatment routine should incorporate measures of physical, mental, social, and role functioning along with overall indicators of general health and quality-of-life perceptions.

Regardless of the WHO's 1948 declaration on health, healthcare worldwide is still dominated by a biomedical interventionist approach which barely recognises other crucial

factors influencing a person's well-being (Gerhardt, 1995). According to Gillespie and Gerhardt (1995), the terms "biomedicine" and the "medical model" describe a natural science-based medical theory and practice, which focuses on the internal physiological workings of the body. From this viewpoint disease and illness are fundamentally the absence of health. White (2002) stated that the medical model explains disease and illness as the result of the invasion of a germ or virus into the individual's body. The cure is the administration of drugs or the use of technologically based treatments (Engel, cited in White, 2002). White (2002) argued that this approach does not take into account that individuals also live in social groups that may have as much to do with their illnesses and diseases as germs and viruses. He referred to tuberculosis as an example of an illness where living conditions play a major role in whether or not the disease develops. Consequently, this approach regards medical knowledge as purely scientific, and disease can be thought of as a product of nature that exists separately of society, and as such is not affected by social, cultural, political and economic variables (White, 2002).

Although biomedicine has been the dominant paradigm in modern western healthcare, alternative social models of illness and health have questioned its assumptions about the causes of illness and death. White (2002) stated that the social sciences maintain that the concepts of illness and health have a far greater complexity than that suggested by the medical model. The social model stresses the need to recognise that scientific and medical "facts" themselves are a specific way of perceiving illness and disease. According to Gillespie and Gerhardt (1995), such "facts" deny people's own interpretations and understanding of the world and prevent any in-depth consideration of root social causes. They also deny the degree to which historical, social, cultural, political and economic factors shape the causes, perceptions and experiences of illness and health. Consequently, the medical model and its biomedical theories and practices are subject to continuing criticism from writers within especially the social sciences.

3.2 Medicalisation critique: a broad perspective

The medicalisation critique has been one of the most dominant perspectives in the sociology of health and illness since the 1970s and into the 1980s. One of the most determined advocates of the medicalisation critique, Ivan Illich, argued that rather than improving people's health, scientific medicine undermined it, both through the side-effects of medical treatment and by diminishing lay people's capacity for autonomy in dealing with their own healthcare (Helman, 1994; Lupton, 1997; White, 2002). According to Gerhardt (1995), Illich emphasised a recurrent theme in his holistic approach to health, namely the need for spiritual and personal dimensions in coping with illness and disease. Illich (cited in Gerhardt, 1995) stated that "suffering, healing, and dying, which are essentially intransitive activities that culture taught each man, are now claimed by technology as new areas of policy-making and are treated as malfunctions from which populations ought to be institutionally relieved" (p.76). In contrast, holistic approaches to health are concerned with finding ways of dealing with illness and disease through gaining greater understanding of individuals, the contexts in which they live, their social and mental states, and their own beliefs (Gerhardt, 1995).

According to Lupton (1997), proponents of the medicalisation critique generally take an overwhelmingly negative view of members of the medical profession, seeing doctors as attempting to increase their position of power by presenting themselves as possessing the exclusive right to define and treat illness, thereby subordinating the views and experiences of lay people. The medicalisation critique further accentuates that this expanding power of scientific medicine has detrimental effects for traditionally disempowered and oppressed social groups by excluding questions of social inequality in the realm of illness and disease (Helman, 1994; Lupton, 1997). Advocates of this critique propagate strategies for "de-medicalising" and the diminishing of medical power, which, it is assumed, would improve the lot of lay people by rendering them greater autonomy and control over their own health states.

Lupton (1997) pointed out that although the medicalisation critique represents an imperative shift in thinking among medical sociologists in calling attention to the possibility for inequality in medical encounters and the provision of healthcare, the critique may itself be criticised for a number of reasons. According to her, one major point of criticism is the diminutive recognition of the ways that medicine and doctors can contribute to good health, the relief of pain and recovery from illness, or the value that many people rightly place on these outcomes. De Swaan (cited in Lupton, 1997) argued that the power of the medical profession to make judgements about normality in terms of illness and health involves complicity on the part of their clients or patients. This complicity unavoidably involves underlying conflict and resistances, "a shifting balance between manifest collaboration and tacit opposition in the relations between those who come for help and those who profess to provide it" (De Swaan, cited in Lupton, 1997, p.98). According to these writers, there exist a hidden agreement and understanding between the dominant party (doctors) and the less powerful party (patients) that reproduce medical dominance.

3.3 Foucault and the medicalisation critique

In medical sociology, Foucault's writings have challenged some central viewpoints of the orthodox medicalisation critique, especially in relation to its conceptualisation of power and medical knowledge (White, 2002). Foucault's writings emphasised the positive and productive rather than the repressive nature of power:

> What makes power hold good, what makes it accepted, is simply the fact that it doesn't only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms knowledge, and produces discourse. It needs to be considered as a productive network, which runs through the whole social body, much more than as a negative instance whose function is repression. (Foucault, cited in Lupton, 1997, p.98)

Foucault (cited in Lupton, 1997) argued that various medical paradigms, over time, have offered systems of knowledge and related practices by which human beings have not only

understood but also experienced their bodies, and for this reason medical power may be seen as the underlying resource by which illnesses are identified and dealt with. According to Lupton (1997), this viewpoint fits into the broader social-constructionist approach in understanding medical knowledge not simply as factual, but as a belief system shaped through social and political relations:

> The power that doctors have in relation to patients, therefore, might be thought of as a facilitating capacity or resource, a means of bringing into being the subjects 'doctor' and 'patient' and the phenomenon of the patient's 'illness'. From this perspective, doctors are not considered to be 'figures of domination', but rather 'links in a set of power relations', 'people through whom power passes or who are important in the field of power relations'. (Foucault, cited in Lupton, 1997, p.99)

In contrast with the orthodox medicalisation critique, a Foucauldian perspective consequently claims that it is not possible to remove power from members of the medical profession and hand it over to patients. "Power is not a possession of particular social groups, but is relational, a strategy which is invested in and transmitted through all social groups" (Lupton, 1997, p.99).

Lupton (1997) referred to data, obtained from her own empirical research using interviews with both lay people and medical practitioners, which suggested that the medical encounter involves a continual negotiation of power that is contingent upon the context in which the patient interacts with the doctor. She further stated that factors such as the type of medical complaint, the age, ethnicity and gender of the patient and doctor, emotional dimensions and the patient's accumulated embodied experiences all shaped the encounter in different ways. Lupton (1997) found in her study that the majority of lay people interviewed continued to want to place their trust and faith in their doctor, and appreciated the doctor showing an interest in their lives. Especially for those people who had experienced serious illnesses or hospitalisation, it was crucial that they felt they could rely on their doctors.

Lupton (1997) concluded that although there are differences between the medicalisation critique and Foucauldian interpretations of scientific medicine, they both agree that medicine is a major establishment in Western societies that play an ever more valuable role in everyday life, influencing the way people think about and experience their bodies. She further stated that there is, however, less agreement on how detrimental this influence is on members of the lay population and what type of action is necessary in response.

Advocates of the medicalisation critique routinely call for strategies for "de-medicalisation" that are assumed to improve the lot of lay people by giving them greater autonomy, control and freedom regarding medical matters and their own bodies. Lupton (1997) stated that from a Foucauldian perspective, "de-medicalising" the body, by focusing on preventative health activities and encouraging lay people to actively acquire more medical knowledge, may lead to different, but not more true forms of subjectivity and embodiment. She argued that neither the medicalisation critique nor the Foucauldian perspective has adequately considered or explained the reciprocal reliance and the emotional and psychodynamic dimensions of the medical encounter.

3.4 Feminist perspectives on illness and health

Regardless of the above observations on the medicalisation critique, it still remains a major and influential approach to illness and health, particularly for feminist critics of medicine. Although there are different feminist perspectives on illness and health, feminists in general argue that medicine and patriarchy control women by enforcing passivity, dependence and submission as appropriate feminine traits (White, 2002). According to White (2002), feminists' key argument is that the way in which we are socialised into masculine and feminine social roles will have a determining effect on our health and illness. They further proclaim that aspects of women's lives regarding their reproductive capacity have been medicalised.

According to the feminist health movement in the United States in the late 1970s the problem that women patients faced was twofold: a medical system that allowed patients very little control over their own care, together with medical knowledge and practices that ignored many of women's needs (Lorber, 1997). The cause, they argued, was a medical system dominated by men and men's values. In medical textbooks, men's bodies were the norm and women's bodies' deviations from the norm (Scully & Bart, cited in Lorber, 1997). Lupton (1997) and White (2002) stated that feminist writers have viewed the medical profession as a mainly patriarchal institution that uses definitions of illness and disease to uphold the relative inequality of women by drawing attention to their weakness and vulnerability to physical illnesses and by taking control over areas of women's lives such as pregnancy and childbirth.

Furthermore, the incidence of illness and death for women is significantly affected by the behaviour of healthcare providers, the policies of healt-care institutions and agencies, and the financial support of national governments for research, treatment and care (McKinlay, cited in Lorber, 1997). Lorber (1997) discussed recent data on medical practice which indicated that gender makes a meaningful difference in two ways: women and men patients are treated in a different way, and women and men physicians treat women patients differently. For instance, women are less likely than men to be routinely tested for cardiovascular symptoms and are more likely to suffer unrecognised heart attacks (Hendel & Mendelson; McKinlay; Wingard et al., cited in Lorber, 1997). Studies show that women physicians are more likely to order cancer-screening tests (Lurie et al., cited in Lorber, 1997) and cholesterol testing (Kreuter et al., cited in Lorber, 1997) for women patients than men physicians do. Although more attention has been given in the past decade to research projects focusing on women's medical needs in general as well as the incorporation of women in drug trials, it is by far not enough (Lorber, 1997).

Concerning AIDS, Cohan and Atwood (1994) stated that, although HIV infection affects women differently than men, this had not been adequately studied and the formal definition of AIDS did not include the manifestation of any gynaecological symptoms. Lorber (1997) pointed out that there were several reports that the symptoms of women

with AIDS were different from those of men, but it took protests at AIDS conferences and legal procedures before the U.S. Center for Disease Control (CDC) changed the list of diagnostic signs of AIDS, adding recurrent and virtually untreatable vaginal yeast infection and invasive cervical cancer. Many feminist writers argued that further attention is needed to mainstream the knowledge about women's bodies, physical illness symptoms, and illness risks into general medicine, especially in the field of AIDS, so that inequalities in medical treatment can be erased and specific health needs of women appropriately addressed.

In the field of psychiatry the medical model also asserts that women are biologically more vulnerable to certain mental disorders, especially depression. Women are regarded as being particularly at risk during periods of hormonal change such as menstruation, following childbirth, and at menopause (Unger et al., 1996; White, 2002). Unger et al. (1996) argued that a major problem with such a medical model is that it defines women almost entirely in terms of their reproductive functions: "In effect, they see a direct connection between the uterus and the mind" (p.558). Greenspan (1993) emphasised that male practitioners who most often diagnose and treat female patients dominate the mental health system; "it is a picture in short of Man as Expert and Woman as Patient" (p.6). According to her, the most significant is the male standard that is implied to be that of the healthy human being. Greenspan (1993) argued that the problem is not that of female mental illness, but the symptoms of such illness, which are for the most part the systematically socially produced symptoms of sexual discrimination. She further explained that the problem is a matter of how women are seen and treated both inside the health system and in the surrounding society as a whole.

3.4.1 Social-constructionist feminist healthcare

Feminist healthcare as an alternative perspective to treating illness, rooted in social-constructionist theory, sees the patient and the healthcare professional as equals in the medical encounter (Lorber, 1997). The medical professional knows more about illnesses

and their treatment in general, but the patient knows more about her or his particular situation. Lorber (1997) argued that for patients a chronic illness condition is a significantly different situation than complete cure; “a cure restores them to their former roles, a chronic condition forces them to modify those roles and establish new patterns of behaviour” (p. 4). She further stated that in a similar way physicians may see treatment side effects as unavoidable, being part of a necessary treatment plan, whereas patients may experience side effects as unwarranted increased pain or discomfort, stress and financial cost. Advocates of feminist healthcare recommend that before the professionals apply general medical science or any form of treatment, they should understand patients’ social and environmental contexts and also patients’ history of the particular disease (Candib, cited in Lorber, 1997).

According to Lorber (1997), to actually understand the incidence and transmission of any disease social epidemiologists have to consider the following: a population’s body typologies, social customs and practices that affect bodies directly (what people eat, drink, smoke), social environments (where people live, the work they do), social and sexual networks that shape individual behaviour and give emotional supports, and access to healthcare resources, technology, and knowledge. Therefore to plan and provide context-grounded health practices, the whole life of a woman within her specific sociocultural context must be taken into account to understand the cause and effects of a series of symptoms and to determine the most effective course of treatment and adaptation to impaired capabilities.

Thus, to understand how best to help women it is necessary to understand who women are, and this can only be done if we understand the society and circumstances in which women live. To achieve such an understanding, women should be granted the opportunity by healthcare workers to explain the context of a particular illness episode and its time span (Greenspan, 1993). Candib (cited in Lorber, 1997) stated that the healthcare professional must in turn accept the patient’s experience in shaping his or her way of looking at the world as valid and, most importantly, show, by listening attentively, that she or he respects the patient’s interpretation of circumstances surrounding the illness.

According to Fisher (cited in Lorber, 1997), it is a well-known fact that patients have to battle to make themselves heard in most medical encounters and that a more open approach on the part of the practitioners would help expose the multi layered and intricate aspects of illnesses between different cultures and between women and men.

According to Greenspan (1993), this wider perspective on treating women's illnesses or pathology incorporates skills that have been absent from the traditional male orientation, inter alia compassion, empathy, intuition and nurturing. She further stated that these are all culturally "feminine" skills, which are in fact essential for the treatment of both women and men. Lorber (1997) emphasised that a social-constructionist feminist approach to healthcare could benefit all patients, men as well as women. She concluded that, although an idealistic goal, if shared by both the providers and the consumers of care, it could in the long run empower the most powerless – the poor, the young, people of colour, the less educated, and women.

3.5 The social construction of illness and health

The viewpoint of social constructionism, as influenced by poststructuralism, second-wave feminism and Foucauldian teaching, has begun to receive increased interest in the study of illness and health. According to social-constructionist theory, the meaning and experience of an illness can be different for different people. Moreover, health professionals and patients can perceive the same set of symptoms in a completely different way (Gwyn, 2002; Lorber, 1997). It has been said of Western medicine that the patient comes to the physician's office with an illness but leaves with a disease. Gwyn (2002) and Treichler (1999) stated that disease is thus taken to represent the medical model and illness the patient's subjective experience. Armstrong (cited in Hydén, 1997) affirmed that doctors from the turn of the previous century onwards have been inclined to treat the reports of patients with considerable scepticism:

> The clinical gaze of the medical profession was focused on the inner bodily world of the patients. How patients spoke about their ills, symptoms and problems was

> regarded at best as a pale reflection of the language of the organs and tissues and their pathological changes. (p.48)

Lupton (1995) pointed out that until recently, the experiences of people affected by illness hardly ever received the attention of medical writers:

> The history of medicine tended towards documenting the discoveries of the 'great men' in biomedical science in the inexorable progression towards modernity. The ways in which people dealt with illness or disease, how they felt about their body and its ills, their relationship with the medical profession and other healthcaregivers, their experience of treatment were aspects of the medical encounter which were little explored. (p.80)

Thus the narratives of patients regarding their subjective experience of an illness within their social environment were, and are up to now, not of great importance to most medical professionals (Good & Good, cited in Lorber, 1997; Hydén, 1997). Visible physical symptoms or clear test results that present a clear diagnosis with an appropriate treatment plan are therefore the ideal illness situation for medical practitioners. Helman (1994) and Lorber (1997) emphasised that the main aims of medical practitioners are curing illnesses by removing physical symptoms and restoring normal functioning to a reasonable level. Consequently, the reciprocal influence and relationship between social context and bodily experiences such as illness are disregarded to a great extent in the medical field.

Treichler (1999) argued that the biomedical model describes entities and phenomena, like viruses and diseases, which are transcultural and natural, but on the other hand it is the human body, the perceiving self, that gives the virus its host environment. She pointed out that it is this person who experiences and reports its effects, and undergoes treatments (and cognitive and affective events) that may change both the environment and the virus. Treichler (1999) contended that from a social-constructionist perspective the patient's view must always be honoured and therefore the medical professional must consequently be urged to recognise and understand the patient's construction of reality.

Lupton (1995) argued that the social-constructionist approach to illness does not necessarily call into question the reality of bodily experiences or illness states, it merely accentuates that these states and experiences are known and interpreted by way of social activity and therefore should be carefully thought about and studied using cultural and social analysis. From this point of view illness is located in the human body, but as a social experience it goes far beyond physiology. According to Gwyn (2002), illness tends to correlate with the psychological, moral and social explanatory models of any given culture, so that the same objectively defined disease would not be experienced as the same illness by individuals in distinct societies. Brown (cited in Lorber, 1997) emphasised that for patients and healthcare professionals, illness entails all the patterns of social life, interwoven social roles, power and conflict, social statuses, networks of relatives and friends, bureaucracies and organisations, social control, beliefs of moral worth, aspects of work and occupations, definitions of reality, and the making of knowledge.

Lorber (1997) demonstrated the above by comparing two illnesses, pneumonia and gonorrhea, both treatable by antibiotics and curable, but with the social effects of pneumonia being very different from the social consequences of gonorrhea. The person with gonorrhea would most probably keep the diagnosis a secret for fear of moral criticism, avoidance or rejection, both by lay people and professionals. Turner (cited in Treichler, 1999) stated that, with regard to sexually transmitted diseases in general, the diseased are seen not as “victims” but as “agents” of biological disaster. According to Lorber (1997), the stigma attached to illness that is sexually transmitted, the result of substance abuse or highly infectious, could violate a person’s social identity and worth, even after return to normal functioning.

AIDS as illness is thus a socially constructed entity, not merely a biological phenomenon. Gilman (cited in Crystal & Jackson, 1992) affirmed that the social construction of AIDS has a significant effect on societal and personal responses to the illness and, therefore, the experience of people with AIDS. Strebel (1993) stated that these social meanings and consequences influence individual experience, public view and policy formation, a process

that in turn reflects the values and concerns of society. Brandt (cited in Treichler, 1999) described AIDS, like other epidemic diseases, as a "natural experiment" in how societies respond to disability, dependence, fear, and death. Society's response reveals its most fundamental cultural, social and moral values.

According to Treichler (1999), the importance of the AIDS epidemic as a social and cultural as well as a biomedical crisis was already widely acknowledged in the late 1980s. She referred to the Fifth International AIDS Conference in Montreal in 1998 that was titled "AIDS: The Scientific and Social Challenge", where more social and cultural presentations featured than in past years. Morisset (cited in Treichler, 1999) compared previous international conferences on AIDS with the 1998 conference in Montreal as follows:

> Originally the meetings dealt almost exclusively with biomedical topics... yet scientists soon had to admit that AIDS is not simply a medical problem, but also a human drama. Naturally, we all know that the ultimate solution will eventually come to light in a laboratory. But meanwhile, what can the virologist or microbiologist offer an AIDS victim and his or her loved ones to ease the burden? To help them combat the ignorance and intolerance they face, which are growing day by day. (pp.149-150)

Treichler (1999) stated that, quite unexpectedly, several factors came together to dispute biomedical control over the epidemic, as participants at this conference asked many questions about HIV: how it worked, how it did damage to the body, how it could be the sole cause of AIDS. Even as the conference overwhelmingly confirmed that this particular virus had almost certainly become a reality too costly to give up, questions about HIV focused attention on the cultural construction of AIDS and, particularly, its construction within the culture of biomedical science (Treichler, 1999). According to Treichler (1999), Montreal did not change AIDS science or science writing, but it did call attention to disjunctures in the meaning of AIDS, to "the AIDS virus" as a constructed entity across several discourses, to the function of metaphors in showing up privileged versions of reality, and to the significant investment in the perception that reality exists out there to be discovered.

Treichler (1999) emphasised the need for an epidemiology of signification, a comprehensive mapping and analysis of the numerous meanings of AIDS, to form the foundation for official definitions that would in turn symbolise the politics, regulations, rules and practices concerning AIDS. According to her these may rest on facts, which in turn may rest on the deeply entrenched cultural narratives of people that urgently need to be heard. Treichler (1999) stated that AIDS exists at a point where many deep-rooted narratives intersect, each with its own momentum and context in which AIDS acquires meaning. Many writers have emphasised that language is crucial to this process of negotiation of meanings.

3.5.1 Social constructionism, AIDS and language

Frankenberg (cited in Leclerc-Madlala, 2001) stated that the term AIDS is overloaded with proliferating and contested meanings concerning notions of clinical disease, social disease, contamination, discrimination, economic and material inequities, religious principles, morality, sexuality, deviance, blame and death. He further stated that these are but some of the notions assigned to the term AIDS which are embodied in its meaning within a given context.

According to Treichler (1999), we cannot effectively analyse an illness condition such as AIDS or develop intelligent social policy if we reject conceptualisations of AIDS. She stated that illness is metaphor and that there have to be efforts to make sense of AIDS.

> Our social constructions of AIDS (in terms of global devastation, the threat to civil rights, the emblem of sex and death, the post-modern condition, whatever) are based not on objective, scientifically determined 'reality' but on what we are told about this reality: that is, on prior social constructions routinely produced within the discourses of biomedical science. AIDS as infectious disease is one such construction. There is a continuum, then, not a dichotomy, between popular and

> biomedical discourses (a continuum between controversies in daily life and those occurring in the laboratory), and these play out in language. (Treichler, 1999, p.15)

Lupton (1995) argued that the use of language when referring to disease and those at risk of contracting it has a direct effect on the manner in which ill people handle their condition and the ways in which others treat them. As Clatts and Mutchler (cited in Lupton, 1995) commented with reference to AIDS:

> To say someone has AIDS is to say much more than that person is experiencing the progressive exposure of fragile vital organs to the ravages of common infections. It is to say that he is or she is a certain type of person, socially and morally defined ... the metaphoric predication of AIDS opens a door to the dark musty cellar of cultural associations of the profane, the defiled, the denied, the unshown, the forbidden, the feared. (p.57)

In Sontag's essay on the metaphors of AIDS (cited in Lupton, 1995), she described AIDS as attracting the same metaphors of invasion as cancer, but also those of pollution, indicating intrusion from outside rather than from within. According to Sontag (cited in Lupton, 1995), the virus (HIV) that causes the immunodeficiency characterised by AIDS is symbolised as an invader of the body, eliminating its defences and allowing the opportunistic infections associated with the onset of AIDS to conquer the body: "Cancer makes cells proliferate; in AIDS cells die" (p.58). She compared AIDS to plagues which are invariably regarded as judgments on society, since they inspire centuries-old fears of incurable illness, spread mysteriously and taking the lives of large numbers of people almost without warning. Metaphors used to give meaning to AIDS such as "the wrath of God" and "silent assassin" emphasise the stigmatised nature of the illness and the discriminatory social attitudes towards and treatment of people with HIV/AIDS (Lupton, 1995). Consequently, AIDS is depicted as punishment for, inter alia, living unhealthy and destructive lives, for taking health risks, weaknesses of will, self-indulgence and addiction (Gwyn, 2002).

Lupton (1995) discussed the use of discriminatory language in an article entitled “Self Destruction”, published in a weekly Australian community newspaper as part of a series of regular medical columns, written by a highly acclaimed medical professional. Lupton (1995) argued that the title of the article itself implies blaming the victim and punishment; “the illness is self destruction, not externally imposed destruction, and it is the body turning against itself” (p.65). While these social constructions are often contradictory and multiple, Plummer (cited in Strebel, 1993) suggested that there are two central discourses which organise much of what he called “AIDSPEAK”, one focusing on the stigmatisation of AIDS and the other on the medicalisation of AIDS.

According to Sontag (1999), the sociolinguistic construction of AIDS focuses our attention on the acute disease model of HIV illness, thereby leading individuals and societies to think in terms of a devastating, perceptible, extremely stigmatising state of being, inevitably leading to death over a relatively short time span. Even though there is an increasing tendency among medical and research personnel to speak of HIV illness rather than AIDS, this shift is by no means systematic and the epidemic is still commonly spoken of as the “AIDS epidemic” (Crystal & Jackson et al., 1992). Consequently, the above language use keeps the focus on persons dying of AIDS as a disease rather than on persons living with HIV as an illness.

From a social-constructionist perspective language is the most important tool used by people with HIV/AIDS to make sense of their world, to interpret and describe their illness experiences. In the present study the focus is on the experiences of women living with HIV as an illness and their construction of the illness through their particular use of language.

3.5.2 AIDS, social status and power

In the literature it is clear that women’s and men’s illness and health are deeply embedded in the social order. Lorber (1997) stated the following:

> Gender, together with race, culture, and social class, constitutes the grounding for individually experienced pathologies. The expert knowledge for comprehensive healthcare has to start with social worlds – of women and of men of different races, cultures, religions, and economic classes – and work back from social processes to their impact on bodies. (p.102)

Collins (cited in Schneider, 1992) argued that it is impossible to understand the particular situation and experiences of the vast majority of HIV-infected men and women without giving serious attention to the intersection of gender, class and race. Schneider (1992) stated that gender, class and race are the three social factors most determinant of a person's health status and his or her degree of well-being. According to Lorber (1997), AIDS is an epidemic infused with gender, sexuality, class, race, and ethnicity:

> How HIV-positive status and the symptoms of AIDS are reacted to and treated reflect heterosexual, bisexual, and homosexual relationships; the constellation of patient, practitioners, and lay caretakers; community attitudes; cultural values; and the politics of medical bureaucracies and government agencies. From negotiations over condom use between sexual partners to allocation of funds for research and treatment by national and international agencies, AIDS literally and figuratively embodies the material, experiential, and symbolic gendered construction of illness. (p.11)

Lorber (1997) confirmed that illness, as a social phenomenon, has to be gendered because gender is one of the most important statuses in any society. Lorber (1997) pointed out that gender is socially constructed, because girls and boys are taught their society's expectations of acceptable behaviour; they grow up to perform their society's gendered social roles. She further stated that gender is a social institution that channels interaction in everyday life and in major social organisations. According to Lorber (1997), gender not only influences the experience of illness and health by way of work and family responsibilities, but also by way of economic circumstances, lifestyle choices, social contact and interaction with family members and friends, as well as interactions with health professionals and health workers (Lorber, 1997). Lorber (1997) pointed out that divisions

on racial, ethnic, educational, occupational and social class-level are often ignored in comparisons of women and men:

> From the recognition and attention to symptoms through actions while sick to coping with recovery or a chronic condition or dying, all of patients' social characteristics have an effect. Their social networks shape this effect, their work and financial status, their family obligations, and the medical care systems and values of their society. As medical care systems change, so does the behaviour of patients and healthcare professionals. (p.6)

According to Imber-Black (cited in Cohan & Atwood, 1994) a major influence on the approach that healthcare professionals have taken in regard to women and AIDS seems to be a expansion of assumptions and beliefs that physicians and the medical profession have, historically, constructed about women. Every profession develops within the context of a dominant culture, and that culture becomes entrenched in its professional language and imagery (Jordanova, cited in Cohan & Atwood, 1994). According to Cohan and Atwood (1994), sociocultural power and gender biases have filtered through the medical profession and pervaded its approach to matters regarding women's healthcare and AIDS. For instance, the woman-as-mother stereotype is accentuated in media depictions of women as primarily nurturers of those who are HIV-infected. Overall (1991) pointed out that there is no comparable cultural image of men as caregivers to women who are HIV-positive.

Corea (cited in Cohan & Atwood, 1994) stated that the medical profession has traditionally neglected women and research has frequently been limited to male models of health and disease. In the literature it is often mentioned that this is particularly true for HIV/AIDS research because AIDS has remained constructed as a gay man's disease long after there was sufficient evidence that women are susceptible to infection. Byron (cited in Cohan & Atwood, 1994) stated that because women have been excluded from the social construction of HIV/AIDS since the onset of the epidemic, they have been excluded from research projects and drug-testing protocols. According to Hunter (cited in Cohan & Atwood, 1994), this has contributed to even greater problems in obtaining meaningful

access to the best of available treatments at the earliest times. These issues can be divided into three categories: threshold issues of diagnosis, reporting and studying of the disease; insufficient access to testing and treatment; and biased research and development protocols for new drugs (Hunter, cited in Cohan & Atwood, 1994).

According to Cohan and Atwood (1994), contemporary social constructions pertaining to AIDS and the intrinsic gender biases and imbalances of power have converged to raise women's risks for contracting the AIDS virus, limit their access to suitable and adequate healthcare, and consequently determine the progression of their illnesses. Strebel (1993) argued that we are confronted by a complex web of contradictory representations in which the specific historical context of the AIDS epidemic in South Africa, plus dominant AIDS discourses and discourses of gendered power relations, which are both mediated by economic forces, make effective AIDS prevention and treatment especially difficult for women in this country. Lorber (1997) emphasised that sexual behaviour and not sexual classification, together with gender differences in social power should be kept in mind in any discussion of HIV risk factors and treatment options.

Consequently, social constructions relating both to women and AIDS are reflected in how issues of women and HIV are dealt with on the micro- to macro-levels in our society (Cohan & Atwood, 1994). These constructions of women and AIDS have become more than sociological or epidemiological explorations into the relationship of gender and a specific disease. Cohan and Atwood (1994) emphasised that demographic reports alone cannot effectively address the impact of AIDS on the lives of women. According to them, a discussion of the relationship of AIDS and women must incorporate a discussion of the ways in which gender, power relations and disease are culturally defined and imbued with meaning. Reid (1993) stated, "Our goal must be to conduct research that provides a meaningful analysis of gender as it is experienced in many different contexts. We can no longer pretend that we can ignore context and still understand gender" (p.147). According to Luttrell (cited in Reid, 1993), analyses of Black and White working-class women strongly dispute claims for a particular or universal mode of knowing among women. When we listen to working-class women, we gain knowledge of the complex gender, race and class

relations of power that shape how women think and the paradoxical circumstances to which they must react (Reid, 1993).

Lorber (1997) also argued that although gendered power relations have a disadvantageous effect on women's healthcare, from a social-constructionist point of view all social factors should be taken into account when studying the illness experience of HIV-infected women and planning prevention and treatment programmes. Because social factors are so interwoven, gender cannot be isolated from social class, race and ethnicity, or age group. Thus for a woman with HIV/AIDS, her health is as much affected by combined social statuses (gender, race, ethnic group, social class, occupation, place of residence and level of healthcare and services) as by personal choices (Calnan et al., cited in Lorber, 1997; Reid, 1993). In joint action these factors within a specific social context influence perceptions of health and illness, experience of illness states, types and availability of care, predictable illnesses, discourse and interaction patterns of doctor-patient relationships, as well as power relations between women with HIV/AIDS and health professionals within the medical-care system.

3.6 Conclusion

Throughout the literature the reciprocal influence and relationship between social context and bodily experiences such as illness are emphasised. It has been stated that disease is taken to represent the medical model and illness the patient's subjective experience within a specific social context. In biomedicine the main focus has been on finding cures rather than on preventing ill health and providing quality healthcare. Lorber (1997) stated that healthcare in Westernised countries is oriented to individual treatment of specific pathologies and illnesses as they occur, not to strengthening and supporting physical, emotional, and social capacities for living with a chronic, recurrent or life-threatening illness. Holistic approaches to health, on the other hand, are concerned with finding ways of dealing with illness and disease through gaining greater understanding of individuals,

the contexts in which they live, their social and mental states, and their own beliefs (Gerhardt, 1995).

According to Segurado, Miranda and Latorre (2003), the ultimate goal of medical care and psychosocial support should be to increase the duration and quality of women's lives. In the literature it is emphasised that a range of biological, psychological and social issues, impacting on quality of life, determine the overall health and well-being of women with HIV/AIDS. Segurado et al. (2003) stated the following:

> In this context, one should acknowledge that women living with HIV/AIDS have specific needs for care that must be addressed by policies, programs and practices. These are frequently multiple and complex, since these women are often faced with socio-economic stressors that may have a negative impact on physical and mental well-being. A comprehensive approach to care is therefore necessary, one that is able not only to deal with the clinical aspects of the disease, but also to provide opportunities for psychosocial assistance. (p.90)

Many writers argued that if medicine is to be effective, it should be concerned with prevention as well as treatment, with care as well as cure, and with the context of illness as well as intervention (Lorber, 1997; McKeown, cited in Gerhardt, 1995). Fernández-Ballesteros (2003) confirmed that illness affects and is affected by broader aspects of people's lives and that it is impossible to separate illness from an individual's personal and social contexts. These writers stated that the institution of medicine should be concerned with all the influences on health, such as, living conditions, socio-political, economic and nutritional statuses, and individual lifestyle choices.

Consequently, many writers argued that the bias demonstrated in research on health and women results from the lack of attention to social context. Brown and Riger (cited in Reid, 1993) pointed out that although traditional feminists upheld the importance of context, their research and theory generally overlooked the variety of contexts that could affect women's health. Reid (1993) argued that hierarchy and power were mainly discussed in

terms of gender. She further stated that these feminists strove to overturn the use of the male norm, but the influence of both race and class standards did not receive the same attention in research studies on women's health issues.

According to Bohan (1993), to assume that all women judge, think, or relate in a typical and universal manner denies the contextuality that frames their behaviour. Failure to acknowledge the diversity among women may contribute to a depiction of women as a homogeneous class, a "seamless category" (Butler, cited in Bohan, 1993). Nicholson (cited in Bohan, 1993) emphasised that the experiences attributed to women, portrayed as contributing to their "nature", are not timeless and universal but are socially, historically, and politically situated. Denny (cited in Reid, 1993) advised that if research studies aim to serve women of lower socio-economic status, they must be aware of the distinctiveness of sex-role socialisations as they relate to socialisation into a socio-economic class within a stratified social system. Thus, because women's economic status is interwoven with factors such as political power, educational attainment, occupational and various other roles, it is essential that women must be analysed and studied in multiple contexts.

Therefore, to gain a better understanding of the bio-psychosocial impact of HIV/AIDS on poor, disadvantaged and minority women, the main focus of research should be on the women's experiences and understanding of their illness within their specific social and cultural contexts on micro and macro structural levels. The present research study was therefore conducted within a social-constructionist framework, to determine how these women participants experienced their illness in the specific social context within which they were functioning. In the following chapter the research methodology applied in the present study is presented.

CHAPTER 4

Research methodology

The topic chosen for this study was mainly inspired by the researcher's personal and professional involvement in the field of HIV/AIDS. The researcher completed a comprehensive four-week training course, compiled and presented by the Department of Health, on HIV/AIDS and counselling. Thereafter she worked for three years as AIDS coordinator and counsellor for the Department of Health, Winelands Region, at the Stellenbosch Provincial Hospital and various clinics, and she also did bereavement counselling for Stellenbosch Hospice during this time. Most of the clients she saw were from the Coloured community of Stellenbosch and the majority were low-income HIV-infected women with HIV-infected children.

According to Reid (1993), the lack of training with and exposure to low-income populations, predominantly ethnic populations, raises valid concerns about a researcher's capability to assess behaviour and interpret research results. According to her, along with the generally higher level of difficulty of conducting research among non-traditional populations, most psychologists are not trained to work with or study diverse populations. She further stated that the fear and uneasiness associated with conducting socially sensitive research make the situation even more problematic and taxing.

The researcher's in-depth training in HIV/AIDS and extensive exposure to low-income HIV-infected Coloured women helped her to plan and manage the present research study, as well as to assess the experiences of the participants and to interpret results. It was evident to the researcher, through the close contact she had with HIV-infected women, that they experienced many psychosocial concerns and difficulties. This personal perception as well as the emphasis in the literature on the neglect of the needs of HIV-infected women, directed the formulation of the goals of this study.

4.1 Study goal

The goal of this research was to conduct an in-depth study of how low-income Coloured mothers describe their experiences of being HIV-positive.

1.1 Operationalisation of goal

1.1.1 To explore the psychosocial concerns and mental health needs of HIV-infected low-income Coloured mothers in everyday life;
1.1.2 To construct a testable Grounded Theory regarding the illness experience of low-income Coloured mothers;
1.1.3 To recommend guidelines for health workers.

4.2 Research design

The present research study was conducted within a social-constructionist framework. Willig (2001) stated that "research from a social-constructionist perspective is concerned with identifying the various ways of constructing social reality that are in a culture, to explore the conditions of their use and to trace their implications for human experience and social practice" (p.7). The aim of the present study was to understand the psychosocial impact of HIV/AIDS on the women participants. Using a social-constructionist perspective, this meant that the planning and focus of the research design were to determine how these women experienced their illness in the specific social context within which they were functioning.

Because qualitative research enhances the study and understanding of participants' perspectives and personal experiences within their specific social contexts, the research objectives of the present study were formulated within the framework of a qualitative methodology (Kvale, 1983; McGinn, 1996; Riessman, 1994; Schwandt, 1997; Willig, 2001).

Janesick (2000) stated that the in-depth description of people's experiences, places, and events has been the cornerstone of qualitative research.

Willig (2001) pointed out that qualitative research methods are used by researchers with quite different epistemological positions. According to Willig (2001), qualitative researchers tend to be concerned with meaning, and are fundamentally interested in how people make sense of the world. Denzin and Lincoln (2000) stated that qualitative researchers are committed to the naturalistic perspective and to the interpretive understanding of human experience. Qualitative researchers aim to understand how people experience certain conditions (for example, what it means and how it feels to live with a chronic or life-threatening illness) and how people manage particular situations (such as caring for a loved one dying of AIDS without adequate support) (Willig, 2001). Patton (cited in Mertens, 1998) confirmed that qualitative methods would be most appropriate when detailed, in-depth information is needed about certain clients and when the emphasis is on individualised outcomes.

According to Banister, Burman, Parker, Taylor and Tindall (1995), there is no single definition for qualitative research, because qualitative research is part of a debate, not a fixed truth. Mertens (1998) quoted a broad definition of qualitative research by Denzin and Lincoln:

> Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials – case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts – that describe routine and problematic moments and meanings in individuals' lives. (p.160)

Banister et al. (1995) and Mertens (1998) stated that certain key words associated with qualitative methods include complexity, contextual, exploration, discovery, and inductive

logic. Mertens (1998) explained that by using an inductive approach, the researcher endeavours to make sense of a situation without inflicting pre-existing expectations on the phenomena under study. Consequently, the researcher begins with specific observations and allows the categories of analysis to materialise from the data as the study progresses.

Mertens (1998) discussed three probable motives for choosing qualitative methods: a) the researcher's view of the world, b) the nature of the research questions, and c) practical reasons associated with the nature of qualitative methods. Guba and Lincoln (cited in Mertens, 1998) stated that one cannot tell a person's view of the world merely by the research methods he or she chooses, although a person's view of the world should shape his or her choice of methods. Therefore, these writers differentiate between using qualitative methods within a post-positivist or conventional paradigm and using them within the interpretive-constructivist paradigm. According to them, if researchers accept the ontological assumption associated with interpretive-constructivism that numerous realities exist that are time and context bound, they would choose to conduct the study using qualitative methods with the intention that they could gain understanding of the constructions held by people in that context.

Social-constructionist qualitative researchers emphasise the socially constructed nature of reality, the intimate relationship between themselves and what is studied, and the situational constraints that shape inquiry. They seek answers to questions that focus on how social experience is created and given meaning (Denzin & Lincoln, 2000, p.8). Guba and Lincoln (cited in Mertens, 1998) identified qualitative methods as the preferred methods for researchers functioning in the interpretive-constructivist paradigm. Nevertheless, they also acknowledged that quantitative methods can be used within this paradigm when it is suitable to do so.

Ware (cited in Ferenández-Ballesteros, 2003) stated that one of the most imperative advances in the healthcare field has been the acknowledgment of the centrality of the patient's point of view in examining the quality of healthcare outcomes. Fernández-Ballesteros (2003) argued that health assessment, or the application of standardised

procedures that quantify an individual's health, should incorporate measurements of the person's subjective feelings of health, behavioural functioning, and well-being. According to these writers this would contribute to a more comprehensive picture of the person's health status, effects of a disease, and the efficiency and success of healthcare interventions.

Strauss and Corbin (1998) stated that research attempts to understand the meaning or nature of persons' experiences of problems such as chronic illness, addiction and divorce, lend themselves to personally getting out into the field and discovering what people are doing and thinking through the use of qualitative methods. "Qualitative methods can be used to obtain the intricate details about phenomena such as feelings, thought processes, and emotions that are difficult to extract or learn about through more conventional research methods" (Strauss & Corbin, 1998, p.11). According to Stanfield (cited in Mertens, 1998), these methods are also most suited when one is studying ethnic minorities and people from disadvantaged communities. Patton (cited in Mertens, 1998) noted that many educational and psychological programmes are based on humanistic values and therefore researchers may well prefer the type of personal contact and data that emerge from a qualitative study. Furthermore, qualitative methods may also be chosen when no acceptable, valid, reliable, appropriate quantitative measure is available for the desired outcomes of a programme or for a specific research population, such as minority or disadvantaged groups.

For the present research study a qualitative method was chosen because of a lack of knowledge about the research problem in this community, the sensitive nature of the research problem, and the participants being from a disadvantaged minority group. Furthermore, the aim of this research project was to observe, analyse, and describe phenomena, rather than to generalise from the findings emanating from the data. Qualitative research methods enhance the rich descriptions of participants and consequently such detail prohibits the developing of generalisations. For this reason semi-structured in-depth interviews were used to gather information. According to Willig (2001) semi-structured interviewing is the most widely used method of data collection in

qualitative research in psychology and is well-matched with Grounded Theory as method of data analysis. The qualitative data were analysed according to constructionist Grounded Theory, thus categories were constructed from the data and interrelationships found between categories. Theory was then generated in an inductive way, as opposed to the deductive ways in which it is typically generated in empirical social studies.

4.3 Participants

4.3.1 Sampling

Theoretical sampling was done in accordance with Grounded Theory principles (as discussed in section 4.6.2.2 of this chapter). This means sampling for theory construction, not for representativeness of a given population (Charmaz, 1995). In this study the Grounded Theory principle of theoretical sampling was used in recruitment, that is to say certain respondents or material were selected because the researcher thought they would be helpful to clarify initial research categories and questions (Charmaz, 1990).

According to Berman (1993), it is problematic to find people who are HIV-infected and willing to share their personal experiences, because of the stigmatisation of the illness. Leclerc-Madlala (2000) and Strebel (1993) emphasised the strong "discourse of silence" among South African women with HIV/AIDS. Because of the researcher's privileged position as HIV/AIDS coordinator/counsellor, 11 suitable and willing HIV-infected Coloured mothers were recruited by means of convenience sampling to make up the total number of participants taking part in this study. There is no hypothesis about a real or universal construction and understanding of HIV/AIDS, thus no generalisations will be made on the findings emanating from the data in this study.

In the literature it is stated that disadvantaged women in their child-bearing years (20 to 40 years) are considered to be the most vulnerable for contracting HIV/AIDS. It is also emphasised that these women/mothers experience high levels of psychosocial distress on

a daily basis that can be ascribed to contextual and sociocultural issues, such as poverty, childcare responsibilities, responsibilities for giving care to others infected with HIV, and the differential stigma and social isolation accompanying an HIV-diagnosis (Catz et al., 2002; Hackl et al., 1997; Tallis, 1998; Withell, 2000). Consequently, these women have to cope with their own illness, as well as numerous other stressors, without adequate psychosocial care and support. Because of these factors, the criterion of being a mother of a child or children was included.

Criteria for participants were: a) HIV sero-positivity; b) being a mother of a child or children. The 11 participants were all Coloured women who spoke Afrikaans as their first language. All 11 participants were direct referrals from municipal clinics and the Provincial Hospital in Stellenbosch, Winelands Region, to the AIDS counsellors at the Stellenbosch Hospice for information, counselling and support. All the participants had been diagnosed HIV-positive through an AIDS-related illness or infection, or an antenatal or postnatal check-up, and they were all mothers of children.

4.3.2 Questionnaire on socio-demographic and health-related items

In the interview schedule (Addendum C, p.361) a selection of close-ended questions was compiled to gather specific socio-demographic information such as age, marital status, education, income, and number and age of dependants. The health-related questions followed the socio-demographic section. Close-ended questions were mainly used to gather health-related information such as time since HIV-diagnosis, risk factors for HIV, and current HIV-status of children. The physical illness symptoms of the women participants were determined by presenting an open-ended question. The above variables were considered relevant for understanding the illness-related experiences of these women.

Socio-demographic and health-related data were pre-coded in specific categories and are presented in three separate tables: Table 1: Demographic details of women participants (p.66), Table 2: HIV-diagnosis and physical symptoms of women participants (p.69), and

Table 3: Children and HIV-status (p.71). The socio-demographic details of the participants are discussed in the following section and health-related information is presented thereafter.

4.3.2.1 Socio-demographic information

A summary of the demographic details of the participants can be found in Table 1 (p.66). Most of the 11 participants were in their late twenties and early thirties. The youngest, Sonja, was 22 years and the oldest, Sylvie, was 47 years old. As stated in the literature, AIDS has become one of the major causes of death for women of reproductive age and women of the age group 20 to 40 years constitute the largest population of AIDS cases in South Africa (Sowell et al., 1999; Schable et al., cited in Murphy et al., 2002).

Table 1 indicates that three of the 11 participants were married. Ann and Rosy lived with their husbands, but Sylvie had been separated from her husband for a period of two years prior to the interview. Of the 11 participants, eight lived with their husbands or partners and three lived with family members. Most of the 11 participants stated that they were dissatisfied with their living conditions and that they lived in "compromised and difficult circumstances". Mariana, Hester and Rosy lived in small one-roomed shacks with no electricity or water. Maggie, Joeyce and Elna lived in a house or flat with their extended families and shared a bedroom with their partner and child/ren. These participants had to pay rent to family members and all of them complained about a lack of privacy and family rivalry.

The majority of the participants voiced their need for better housing and living arrangements. Hester, Joeyce and Sonja said:

"In my future also, I feel I'd like to live in my own house someday... We're now going to live in the shacks for another winter, what is that going to cause, will I get so sick again in the winter in the shack." (Hester)

"In my toekoms ook, dit voel vir my ek wil eendag as ek in my eie huis kan woon... Ons gat nou al weer 'n winter nog in die hokkies woon, wat gaan dit nou weer veroorsaak, gaan ek weer so siek raak in die winter in die hokkie." (Hester)

"If I can just get my own place and I get the disability money, the money for the illness, then I can help him (her partner dying of AIDS) and so on." (Joeyce)
"As ek net my eie plek kan kry en ek kry nou die onderhoud geld, die siekte se geld, dan kan ek nou vir hom (her partner dying of AIDS) help en so aan." (Joeyce)

"My biggest wish is that I just want a place of my own, not to board with people in a backyard. I want my own little place, I want a flat or something and to be on my own, me and my child." (Sonja)
"My grootste begeerte is ek wil net 'n plek van my eie hê, nie by mense agter in 'n yard board nie. Ek wil my eie plekkie hê, 'n flat of 'n ding wil ek hê en op my eie is, ek en my kind." (Sonja)

Table 1 shows that most of the participants (10) had finished primary school, with four of them passing grade 9. The average monthly household income was R1 016, with seven of the participants reporting household incomes below R1 000 per month. In most of these households only one or two of the adults were earning a monthly income. In South Africa the poor (classified as the poorest 40% of households) are defined as those earning less than R355 per adult per month (Whiteside & Sunter, 2000). Considering that for the present study the average number of adults per household was four, the majority of these households could be classified as poor. Only two of the participants, Maggie and Sylvie, worked for an income outside the home. All of the other participants, except for Mariana, cared for their families and children and had many household duties. Because of Mariana's serious alcohol dependency, the local welfare services had placed her children in the foster care of her mother. Most of the participants were previously employed and earned an income. The majority of the participants indicated that they would like to work outside the home and earn an income, as in the past, but because of their illness they felt physically and emotionally tired most of the time. They also mentioned that caring for their children and their many household duties kept them from working outside the home.

Table 1

Demographic details of women participants

Code name	Age (in yrs)	Relationship status	Education	Work status	Household income per month
1. Ann	32	Married Lives with husband	Grade 7	Housewife Cares for children	R1 520
2. Maggie	24	Unmarried Lives with partner	Grade 7	General worker at brick factory (full week)	R2 110
3. Mariana	33	Unmarried Lives with partner	Grade 6	None	R500
4. Joeyce	26	Unmarried Lives with partner	Grade 3	Household duties Cares for child	R885
5. Hester	26	Unmarried Lives with partner	Grade 9	Housewife Cares for children	R500
6. Rosy	35	Married Lives with husband	Grade 8	Housewife Cares for child	R500
7. Elna	28	Unmarried Lives with partner	Grade 9	Household duties Cares for child	R1 400
8. Sonja	22	Unmarried Lives with family	Grade 9	Household duties Cares for child	R700
9. Sylvie	47	Separated Lives with family	Grade 7	Baker (full week and Sat. mornings)	R1 600
10. Bertha	28	Unmarried Lives with family	Grade 7	Household duties	R780
11. Nossie	34	Unmarried Lives with partner	Grade 9	Housewife Cares for child	R680

According to Kaplan (1995) and Sowell et al. (1999), areas with higher rates of HIV and AIDS among women, in various countries, appear to be strongly correlated with social problems, including low income, inadequate or insufficient housing, unemployment and low maternal education. Cohan and Atwood (1994) and Murphy et al. (2002) confirmed that limited social support, restricted economic resources, difficulty accessing healthcare services, housing needs, and physical and emotional fatigue are the hard and complex

facets of the lives of most women who are caring for family members with AIDS. Zuma (1998) also emphasised that, inter alia, poverty, illiteracy, poor health services, prostitution and poor women's socio-economic conditions contribute to the spread of the HIV and AIDS epidemic in South Africa. Lachman (1991) stated that the health status of women is affected by the interrelationship between behavioural risk, low income, and poor environment, and not by each factor alone. According to Sowell et al. (1999) and Williams (1995), many women with HIV are socially isolated by factors such as unemployment, being single mothers, and lack of convenient transportation, and as a result are particularly isolated from the healthcare system.

In the literature it is emphasised that these conditions can contribute to a lack of much needed medical treatment and psychosocial support, which can cause women to become ill much sooner, as well as psychological distress such as depression, anxiety and loneliness.

4.3.2.2 Health-related information

4.3.2.2.1 HIV-diagnosis and physical symptoms of women participants

As has been stated in Chapter 1, in terms of the global HIV/AIDS picture, sub-Saharan Africa is somewhat of a discrepancy, with more women than men infected with HIV and dying of AIDS (UNAIDS, 2000). Women's greater susceptibility to HIV infection through heterosexual transmission can be explained as the outcome of both biological and social factors. In sub-Saharan Africa more than 80% of HIV cases in women are caused by vaginal intercourse, with less than 10% of infections attributable to contaminated blood products or unsterilised equipment used for health treatments (Laird, 2001). Table 2 (p.69) indicates that for all of the participants in the present study, HIV infection occurred through heterosexual intercourse.

The majority of the participants in the present study were tested for HIV during antenatal visits at their local clinic or shortly after the birth of their only or youngest child. Table 2 shows that the time since diagnosis varied from three months to four years. Eight participants had been diagnosed for one year six months or less at the time of the interviews. The remaining three participants, Joeyce, Hester and Rosy, had been diagnosed for three years six months or more at the time of the interviews. Participants who had been diagnosed for more than one year generally reported more physical symptoms than those women diagnosed for 12 months or less. At the time of the interviews none of the participants were receiving anti-retroviral treatment (ART) for their illness condition. Being from a disadvantaged community and not having the financial means to receive private medical treatment, the participants had little or no chance of using anti-retroviral medication. As has been discussed in Chapter 1, state health facilities/services did not provide ART for patients until recently.

In the section on health-related items in the interview schedule (Addendum C1, p.361), the participants were presented with an open-ended question enquiring about physical symptoms related to or caused by their illness. The participants reported a wide range of physical symptoms, which influenced their daily functioning and overall quality of life (see Table 2, p.69). These physical symptoms will be discussed in more detail in section 5.3, p.158.

Table 2

HIV-diagnosis and physical symptoms of women participants

Code name	Time since diagnosis	Physical symptoms	HIV risk categories
1. Bertha	3 months	Fatigue; abnormal menstruation (dark colour); increased perspiration; hypersomnia	Heterosexual intercourse
2. Sonja	6 months	Anxiety symptoms: nervousness / feels tense, trembling / shaking of hands	Heterosexual intercourse
3. Ann	6 months	Weight loss; vaginal infections	Heterosexual intercourse
4. Maggie	9 months	Weight loss; fatigue; increased perspiration	Heterosexual intercourse
5. Mariana	12 months	Night sweats; at present waiting for test results for cervical cancer	Heterosexual intercourse
6. Nossie	12 months	Bladder infections	Heterosexual intercourse
7. Sylvie	1 year 3 months	(Hepatitis B) Fatigue; vaginal infections; swollen and painful glands; eyes feel blurry; anxiety symptoms: dizziness	Heterosexual intercourse
8. Elna	1 year 6 months	Weight loss; fatigue; vaginal infections; painful sores on face and lower body; moles under arms and in vaginal area; headaches; anxiety symptoms: dizziness (feels as if she wants to faint)	Heterosexual intercourse
9. Joeyce	3 years 6 months	Weight loss; vaginal infections; bladder infections; swollen and painful glands under arms; persistent cough; anxiety symptoms: trembling / shaking of body; panic attacks; hallucinations	Heterosexual intercourse
10. Hester	3 years 6 months	Being treated for TB Weight loss; fatigue; vaginal infections; swollen and painful glands; sores under arms and in vaginal area	Heterosexual intercourse
11. Rosy	4 years	Fatigue; headaches; night sweats; anxiety symptoms: dizziness; trembling / shaking of body, tightness in chess; panic attacks (feels as if she is dying)	Heterosexual intercourse

4.3.2.2.2 Children and their HIV-status

Because most of the women had been tested for HIV/AIDS during antenatal visits or shortly after the birth of their only or youngest child, the majority of the HIV-positive children were in their toddler years. Table 3 (p.71) shows the number of children each participant had as well as the age category for each child. Seven of the participants had one child who was HIV-positive and one participant had two HIV-infected children. These children had related illness symptoms and obviously needed special care and attention. Of the nine HIV-positive children, eight were younger than six years and one child fell into the age category of six to twelve years. Because of Mariana's serious alcohol dependency problem, the local welfare services had placed both her children, one being HIV-positive, in the foster care of her mother. The oldest participant, Sylvie, who had six children, was unsure of the HIV-status of her two youngest children. She, however, did not mention any illnesses or physical symptoms concerning these children.

In the literature it is emphasised that most women with symptomatic HIV disease are low-income women with young children, thus parenting adds to the experience of fatigue. This may have negative effects on a women's daytime activities and functional status, such as her ability to work outside the home and care for her children and family. This situation deteriorates when one or more of her children are also HIV-positive or symptomatic.

Table 3

Children and HIV-status

Code name	Age of child/ren	Number of children HIV+
1. Ann	1 (0-5 yrs) lives with mother	1 (0-5 years)
	1 (6-12 yrs) lives with mother	1 (6-12 years)
	1(13-18yrs) lives with mother	
2. Maggie	1 (0-5yrs) lives with mother	None
3. Mariana	1 (0-5 yrs) lives with family	1 (0-5 years)
	1 (6-12 yrs) lives with family	
4. Joeyce	1 (0-5 yrs) lives with mother	None
5. Hester	1 (0-5 yrs) lives with mother	1 (0-5 years)
	1 (6-12 yrs) lives with mother	
6. Rosy	1 (0-5 yrs) lives with mother	1 (0-5 years)
	1 (6-12 yrs) lives with family	
	1 (13-18 yrs) lives with family	
7. Elna	1 (0-5 yrs) lives with mother	1 (0-5 years)
8. Sonja	2 (0-5 yrs) lives with mother	1 (0-5 years)
9. Sylvie	2 (6-12 yrs) lives with family	Unsure about 2 youngest
	1(13-18yrs) lives with family	
	3 (18+ yrs) lives with family	
10. Bertha	1 (0-5 yrs) lives with mother	1 (0-5 years)
	1(13-18yrs) lives with mother	
11. Nossie	1 (0-5 yrs) lives with mother	1 (0-5 years)

4.4 Procedure

The objectives of the present study and procedure of the interview schedule were thoroughly explained to the participants at the start of each interview. Each participant was required to sign an informed-consent form after it had been explained by the researcher and read by the participant. All the participants gave their consent to be interviewed. The informed-consent form was compiled in the participants' first language, namely Afrikaans (Addendum B, p.359). The researcher herself conducted the interviews at the local clinics and Provincial Hospital at times that were convenient for the participants. These interviews took approximately two to three hours to complete. The researcher conducted and managed the interviews in an open and relaxed way to build rapport and maintain spontaneity with the participants. Privacy, confidentiality and an empathic-sensitive attitude were of the utmost importance throughout the interviewing process, which contributed to a more open and trusting relationship between the participant and the researcher.

The interview schedule (Addendum C, p.361) consisted of two parts and was applied in the following sequence:

1. Socio-demographic and health-related questions,
2. The semi-structured questionnaire focusing on psychosocial issues.

Interviews were conducted in Afrikaans, which was the first language of all the participants, and fortunately of the researcher as well. This gave the participants the freedom to express their experiences in their own language, which reflected their individual and unique understanding constructed within their particular contexts. A professional translator translated excerpts from the interviews which are used in this document from Afrikaans into English.

4.5 The qualitative measure: semi-structured interviews

In the present study Grounded Theory was applied within the framework of qualitative research. As qualitative measure a semi-structured in-depth interview schedule was developed according to Grounded Theory protocol.

4.5.1 Grounded Theory

Charmaz (1995) summarised the distinctive characteristics of Grounded Theory as follows:

1. Simultaneous involvement in data collection and analysis phases of research;
2. Creation of analytic codes and categories developed from data, not from preconceived hypotheses;
3. The development of middle-range theories to explain behaviour and processes;
4. Memo-writing, that is, writing analytic notes to explicate and fill out categories, the crucial intermediate step between coding data and writing firsts drafts of papers;
5. Theoretical sampling, that is, sampling for theory construction, not for representativeness of a given population, to check and refine the analyst's emerging conceptual categories;
6. Delay of the literature review. (p.28)

Strauss and Corbin (1998) explained Grounded Theory as, "Theory that was derived from data, systematically gathered and analysed through the research process... in this method, data collection, analysis, and eventual theory stand in close relationship to one another" (p.12). According to Charmaz (1995), in Grounded Theory research actual data collection and transcription are not regarded as processes that are totally disconnected from data analysis, but rather as the first major analytic stage of the research which consists of the coding of the data. Charmaz (1995) stated that the grounded theorist's simultaneous involvement in data-gathering and analysis is explicitly aimed towards developing theory.

According to Charmaz (1995), Grounded Theory methods consist of a set of inductive strategies for analysing data. In Grounded Theory the researcher does not begin a research project with a preconceived or clear theory in mind, but rather starts with an area of study and allows categories of meaning and theory to emerge from the data. Thus, Grounded Theory facilitates the process of "discovery" or theory generation (Willig, 2001). Strauss and Corbin (1998) stated that theory derived from data is more likely to come close to the "reality" than theory derived by putting together a series of concepts based on experience or solely through supposition. "Grounded theories, because they are drawn from data, are likely to offer insight, enhance understanding, and provide a meaningful guide to action" (Strauss & Corbin, 1998, p.12).

Willig (2001) stated that "Grounded Theory is both the process of category identification and integration (as method) and its product (as theory)" (p.33). According to her, Grounded Theory as method gives the researcher guidelines on how to identify categories, how to make links between categories, and how to establish relationships between them. Grounded Theory as theory is the end result of this process; it provides us with a descriptive framework with which to understand the phenomenon under study (Willig, 2001). Charmaz (1995) explained that one starts with individual cases, incidents or experiences and develops progressively more abstract conceptual categories to create, to describe and to understand one's data and to identify patterned relationships within it. One begins with an area to study, then one develops one's theoretical analysis on what one discovers is relevant in the authentic worlds that one studies within this area.

A further important characteristic of Grounded Theory is memo-writing, which provides the essential step of breaking the categories into components and elaborating the codes (Charmaz, 1990). Charmaz (1990) explained that through memo-writing, the researcher moves directly into analysis of the data, by systematically examining, exploring and elaborating upon bits of data and initial codes. She further stated that memo-writing leads directly to theoretical sampling, which means collecting more data to clarify ideas and planning how to integrate them with existing categories. According to Willig (2001), theoretical sampling is concerned with the refinement and, ultimately, saturation of existing

and increasingly analytic categories (p.35). In Grounded Theory, in contrast with empirical studies, the review of the literature in the specific field of study only takes place when a conceptual analysis of the data has been developed.

Fundamentally, Grounded Theory methods unite the research process with theoretical development and also obscure the commonly rigid boundaries between the data-collection and data-analysis phases of empirical research (Charmaz, 1995). According to Charmaz (1995), a major contribution of Grounded Theory methods is that they provide systematic procedures for researchers to check, refine and develop their ideas and intuitions about the data. She further stated that these methods enable researchers to make conceptual sense of large amounts of data. Strauss and Corbin (1998) pointed out that even though grounding concepts in data is the main feature of this research method, creativity of researchers is a vital ingredient as well. Patton, a qualitative evaluation researcher, (cited in Strauss & Corbin, 1998), stated that qualitative evaluation inquiry draws on both critical and creative thinking, which are mutually the science and art of analysis.

In the present study the researcher strove to develop and enhance the characteristics and requisite skills necessary to be a grounded theorist, recommended by Strauss and Corbin (1998, p.7):

1. The ability to step back and critically analyse situations;
2. The ability to recognise the tendency toward bias;
3. The ability to think abstractly;
4. The ability to be flexible and open to helpful criticism;
5. Sensitivity to the words and actions of respondents;
6. A sense of absorption and devotion to the work process.

According to Charmaz (2000), Grounded Theory methods can be used by researchers who subscribe to realist, objectivist assumptions as well as by those who subscribe to interpretative, constructionist perspectives. There are further different variations of Grounded Theory applications and there are also variations at different times in the same grounded theorist's use of Grounded Theory methods (Charmaz, 2000). In the literature

two major modes of Grounded Theory methods are primarily discussed: the classic mode as introduced in 1967 by Glaser and Strauss, and Strauss and Corbin's 1990 reformulation of the classic mode (Annels, 1997, p.176). In the present study the Social-constructionist Grounded Theory of Charmaz (1990; 2000) was applied. This method of analysis is briefly discussed in the next section as it had implications for the selection of participants, data collection, the format and use of interviews, transcription of interviews, and data analysis.

4.5.2 Social-constructionist Grounded Theory

Charmaz (2000) pointed out that constructivist Grounded Theory takes a middle ground between postmodernism and positivism, and offers accessible methods for taking qualitative research into the 21st century. Schwandt (cited in Charmaz, 2000) stated that "[c]onstructivism assumes the relativism of multiple social realities, recognises the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects' meanings" (p.510). According to Charmaz (2000), a constructivist approach to Grounded Theory reaffirms studying people in their natural settings and redirects qualitative research away from positivism. Charmaz (2000) argued that: 1) Grounded Theory strategies need not be rigid or prescriptive; 2) a focus on meaning while using Grounded Theory advances, rather than confines, interpretive understanding; and 3) Grounded Theory strategies can be accepted without embracing the positivist leanings of earlier proponents of Grounded Theory.

According to Blumer (cited in Charmaz, 2000, p.525), to develop a constructivist Grounded Theory the researcher should gain an in-depth understanding of the research work and this calls for "intimate familiarity" with respondents and their worlds. Charmaz (2000) stated the following:

> To seek respondents' meanings, we must go further than surface meanings or presumed meanings. We must look for views and values as well as for acts and facts. We need to look for beliefs and ideologies as well as situations and structures.

> By studying tacit meanings, we clarify, rather than challenge, respondents' views about reality. (p.525)

The conceptual level of coding, writing memos and developing categories differs in objectivist and constructivist Grounded Theory (Charmaz, 2000). According to Charmaz (2000), Strauss and Corbin keep close to their representation of unconcealed data. Charmaz (2000) contended that the researcher must rather aim to understand the assumptions underlying the data by piecing them together. She used the example of ill people reporting "living one day at a time" or having "good days" or "bad days" as self-evident facts. According to her it is essential to ask what these terms mean experientially, that is, how they affect the respondents' relating to time, what feelings these experiences elicit, and so forth. She affirmed that questions must aim to get at meaning, and not at truth. Charmaz (2000) further stated that objectivist Grounded Theory studies may offer rich description and make conditional statements, but they may remain outside of the experience. According to her, in these studies terms and categories take centre stage and distance readers from the experience, rather than concentrate their attention upon it. On the other hand, active codes, by making categories consistent with studied life, help to keep that life in the foreground and preserve images of people's experiences (Charmaz, 2000).

Charmaz (1990) proposed a social-constructionist-informed Grounded Theory. From this perspective the researcher is seen as co-constructing the responses of the respondents, by actively constructing the research questions and shaping the research process and the interpretation of the data. Charmaz (1990) explained that the researcher's discipline, own experiences, values and preferences determine research questions, as well as the categories and themes in the data that will be the focus of study. Furthermore, the researcher's discipline provides concepts by which categories will be identified in the data. Charmaz (1990) warned that the researcher must be extremely aware of the categories that she brings to the research and she must be cautious not to merely categorise the data into pre-existing concepts. A social-constructionist perspective will guide the researcher to create categories of the respondents' beliefs and actions and to endeavour to stay as close as possible to how the respondents make meaning of their lived experiences. This will lead to

the development of new meanings that can be supplementary to well-known concepts in a specific discipline. Charmaz (1990) emphasised that social-constructionists strive to know how and why people experience, think, feel and behave the way they do.

According to Reid (1993), the silencing of poor women in psychological research has resulted mainly from psychology's dependence on expert testimony, that is, a reliance on our own interpretations of the experiences of others. She argued that we have not provided sufficient mechanisms to permit diverse groups of women to tell their own stories; instead, we have felt secure in making assertions and drawing parallels, which may be inapt and incorrect. Charmaz (2000) emphasised that a constructivist approach necessitates a relationship with respondents in which they can share their experiences on their terms. According to her it means listening to their stories, with an openness and earnestness to feelings and experience. Hydén (1997) stated that the form of the story, its presentation and organisation, also conveys something of the self-image that the narrator or participant wishes to express:

> The stories people tell are important not only because they offer an unmatched window into subjective experience, but also because they are part of the image people have of themselves. These narrative self-representations exert enormous power. They shape how we conduct our lives, how we come to terms with pain, what we are able to appropriate of our own experience, and what we disown. (Ochberg, cited in Hydén, 1997, p.50)

Charmaz (2000) warned against framing questions in ways that cover raw experience and unspoken feelings. She stated that in studies about suffering and pain, researchers may unintentionally give off cues that they do not welcome respondents' going too deep. Thus the very structure of an interview may prevent private thoughts and feelings from emerging. Charmaz (2000) stated that researchers' continued involvement with research participants decreases these problems. For the present study, the researcher's work, involvement and regular contact with the participants, as well as with numerous other AIDS patients, and her shared understanding of their unique and difficult circumstances, contributed to the development of trusting and meaningful relationships. This contributed to most participants

opening up and sharing their deep and private thoughts and feelings with the researcher, which in turn, provided the researcher with rich, detailed data and explicit materials from which she could create categories of the respondents' own beliefs and actions. Furthermore, during the process of coding and categorising the data, the researcher attempted to stay as close as possible to how the participants made meaning of their illness experiences.

4.5.2.1 Research and interview questions

Generally, grounded theorists start with a set of experiences they wish to explore (Charmaz, 1990). In this study, the research question was: How do HIV-infected low-income Coloured mothers experience their illness? The derivation of this question is discussed in the introduction of this chapter.

To use the Grounded Theory method effectively to explore the research question, the researcher needs rich, detailed data (Charmaz, 1990). In order to develop a durable, useful Grounded Theory, the data must offer a variety of complete descriptions of major issues and processes. By acquiring these data, the researcher is able to portray the research participants' worlds (Charmaz, 1990). According to Charmaz (1990), such data result in researchers' developing analyses more easily with more credible arguments. She further stated that unlike what is the case with most other types of qualitative data, grounded theorists being co-constructors in the research process explicitly shape the materials they gather from the beginning, which provides the basis for later coding and categorising. According to Charmaz (1990), interviewing works well in studies of chronic illness because the researcher usually wants to obtain detailed individual descriptions. The semi-structured interview, being the most widely used method of data collection in qualitative research in psychology, provides an opportunity for the researcher to hear the participant talk about a specific aspect of her life or experience (Willig, 2001). Willig (2001) stated that the challenge for the interviewer is to find the right balance between maintaining control of the interview and where it is going, and allowing the interviewee the space to speak freely and openly. She suggested the use of an interview agenda so that the interviewer does not lose

sight of the original research question. Furthermore, Willig (2001) emphasised that the semi-structured interview necessitates sensitive and ethical negotiation of rapport between the interviewer and interviewee.

In the present study a semi-structured in-depth interview schedule was developed according to Grounded Theory protocol (Addendum C, p.361). This was done after the researcher had consulted local experts in the field. Reid (1993) recommended that to gain useful data, the researcher must share her expertise while learning from those who already are skilled in that specific community. Although the same set of questions was presented in a pre-ordered sequence to the participants in the present study, each participant was given the space and encouragement to respond in their own unique way. Lofland et al. (cited in Charmaz, 1990) stated that the interview should be a "directed conversation", but warned against being too directive, which can result in the researcher losing the most interesting leads and rich data.

To address the broad research question of the present study, respondents were asked about specific behaviours, experiences, thoughts and feelings that related to living with a positive HIV-diagnosis. Questions focused on response to diagnosis, disclosure, intimacy and support, affect, coping, and future concerns and plans. The questions were designed to inquire how the women themselves defined and understood their experiences. Because of the sensitive nature of the questions, privacy, confidentiality and an empathic-sensitive attitude were of the utmost importance, and maintained throughout each interview, which, in turn, contributed to a more open and trusting relationship between the participant and the researcher.

The first two participants who had been recruited and who were willing to take part in the study, were the first participants to be interviewed by the researcher. After these interviews had been transcribed and coded, it was clear that the questionnaire schedule elicited rich, vivid and detailed data. The data offered a variety of descriptions of major issues and concerns in these participants' lives. It was therefore decided not to adapt or change the interview questions and format.

After each interview the researcher also compiled an observational evaluation of her personal experience, thoughts and feelings about the specific interview and interviewee (see Addendum D for a shorter version of these evaluations, p.367). The researcher made use of these memos during the Grounded Theory analysis of the data.

4.5.2.2 Theoretical sampling

In the present study the Grounded Theory principle of theoretical sampling was used in recruitment, which meant that certain respondents or material were selected because the researcher thought they would be useful to clarify initial research categories and questions (Charmaz, 1990). Although Grounded Theory precludes the exact numbers of participants being determined prior to the study, it was anticipated that the participants would be a group of at least 10 Coloured women from the Winelands region of the Western Cape. Finally, 11 women were recruited who represented the range of circumstances faced by most low-income Coloured women with children who are HIV-positive.

Theoretical sampling means collecting more data to clarify ideas and to plan how to integrate them with existing categories (Charmaz, 1990). As discussed in the previous section, the first two interviews conducted in the present study provided the researcher with rich, vivid and detailed data from which initial categories were created. To build on these categories, the researcher proceeded to interview the remaining nine participants. After the transcribing and coding of each interview, the new data was used to check, fill out, and extend theoretical categories. This process finally caused the saturation of categories. According to Willig (2001) theoretical sampling is concerned with the refinement and, eventually, saturation of existing, and increasingly analytic categories (p.35).

Charmaz (2000) recommended that theoretical sampling should only be done after key concepts have been defined. According to her, delaying focused theoretical sampling of data fosters a greater in-depth understanding of the realities and issues at hand. For this reason, theoretical sampling fits best into the research and analytic process much later than

initial sampling of sites, people or documents (Charmaz, 1990). At this point the researcher decides to sample specific issues only, by looking for precise information to shed light on the emerging theory (Charmaz, 2000). According to Charmaz (2000), theoretical sampling helps to develop the emerging categories by making them more definite and useful. Thus the aim of this sampling is to refine ideas, not to enlarge the size of the original sample. At this stage of the analytic process in the present research study, the researcher focused on specific psychological distresses, namely psychosocial losses, loneliness, anxiety and depression that were related to the participants' illness condition, coping strategies, living conditions and social circumstances. The researcher needed to find clarity on the reciprocal influence between these factors.

4.5.2.3 Transcription of interviews

In the present study interviews were audiotaped, transcribed and coded by the researcher according to Grounded Theory protocol. Willig (2001) stated that it is important that the researcher explains why the interview is being recorded and in which manner it will be used. In the present study the researcher addressed this issue at the beginning of each interview when she explained the interview procedure to the participant.

Kvale (1996) stated, "Transcribing the interviews from an oral to a written mode structures the interview conversations in a form amenable for closer analysis. Structuring the interview into texts facilitates an overview and is in itself a beginning analysis" (p.168). According to Kvale (1996), transcription from tape to text involves a series of technical and interpretational issues that should be attended to by the researcher. He suggested that the researcher should start by transcribing one or two pilot interviews. According to Kvale (1996), this would sensitise her to the importance of acoustic quality of the recording, to paying attention to asking clear, audible questions and getting just as clear answers in the interview situation. Kvale (1996) stated that the transcribing experience would also make interviewers aware of some of the many decisions involved in transforming oral speech to

written texts, and it would give an idea of the time span and effort the transcription of an interview requires.

In the present study the researcher transcribed verbatim each interview within a week of conducting that specific interview. This was the best route to take, since the researcher was able to clarify non-verbal communication such as silences, tone of voice, laughter and tears. It was also much easier to shed light on unclear parts or words. After conducting and transcribing the first two interviews, the researcher had a thorough understanding of what the transcribing process entailed and required, and could proceed with the following interviews with more insight and skilfulness.

Kvale (1996) emphasised that transcripts are not fixed data of interview research; they are rather replicated constructions from an oral to a written mode of communication. He further stated that every transcription from one context to another involves a series of judgments and decisions. Because of the constructive nature of transcripts, the reliability and validity of transcripts need to be addressed by the researcher. Kvale (1996) suggested that to enhance transcriber reliability, it is an easy check to have two persons independently transcribe the research material and then to compare these transcripts. According to him this can also be problematic, because it may be difficult for two transcribers to reach full agreement on what was said. Kvale (1996) suggested another way to enhance reliability, namely that the transcriber listens to the taped material for a second time and simultaneously checks the written material. In the present study the researcher followed the second method, which gave her the opportunity to listen attentively to all the participants' narrations for a second time. When necessary, certain parts of a tape were replayed a few times to make certain that words and phrases were interpreted and presented as they had been spoken.

Kvale (1996) stated that determining the validity of the interview transcripts is more complex than assuring their reliability. Kvale (1996) explained that when two transcripts are compared, neither transcription is more objective than the other; they are rather different written constructions from the same oral passage. "Transcripts are not copies or

representations of some original reality, they are interpretative constructions that are useful tools for given purposes" (Kvale, 1996, p.165). Charmaz (1990) advised that it is best when the researcher herself conducts the interviews as well as transcribes the interviews in order to engage with the data from the beginning of the research process. According to Kvale (1996), researchers who emphasise the modes of communication and linguistic style may choose to do their own transcribing in order to secure the many details relevant to their specific analysis. In the present study the researcher chose to conduct and transcribe the research interviews herself, for the primary reason of engaging with the data from the start of the research process. She also wanted to make sure that the idiomatic, unique and descriptive Afrikaans words and phrases used by the Coloured participants were not missed or overlooked.

4.5.2.4 Coding and categorising data

In Grounded Theory, analysis begins early and codes are created as data is collected. Unlike quantitative research that requires data to fit into preconceived standardised codes, the researcher's interpretations of data shape his or her emergent codes in Grounded Theory (Charmaz, 2000). Willig (2001) confirmed that "[g]rounded Theory aims to develop new, context-specific theories; therefore category labels should not be derived from existing theoretical formulations but should be grounded in the data instead" (p. 34). In Grounded Theory coding sets off the chain of theory development. Initial or open coding continues as the researcher examines each line of data and then defines experiences, actions or events within it (Charmaz, 2000).

According to Charmaz (2000), line-by-line coding keeps the focus on the subjects' views of their realities and discourages the researcher from imposing existing theories or his or her own beliefs on the data. She further stated that line-by-line coding sharpens our use of sensitising concepts, which offers ways of seeing, organising and understanding experience. "Line-by-line coding keeps us thinking about what meanings we make of our data, asking ourselves questions of it, and pinpointing gaps and leads in it to focus on during subsequent

data collection" (Charmaz, 2000, p.515). This leads to the generation of action codes, which gives the researcher insight into what people are doing and what is happening in their lives. Generating action codes facilitates making comparisons, a major technique in Grounded Theory (Charmaz, 2000). This constant comparative method of Grounded Theory means:

1) Comparing different people (such as their views, situations, actions, accounts, and experiences),

2) Comparing data from the same individuals with themselves at different points in time,

3) Comparing incident with incident,

4) Comparing data with category,

5) Comparing a category with other categories. (Charmaz, 2000, p.515)

With selective or focused coding initial codes that reappear frequently are used to arrange large quantities of data. These codes account for the most data and categorise them most accurately. According to Charmaz (2000) making explicit decisions about selecting codes gives us a check on the fit between the emerging theoretical framework and the empirical reality it seeks to explain. She further stated that categories for synthesising and explaining data arise from focused codes and sequentially shape the development of analytic frameworks. Charmaz (2000) pointed out that categories often include several codes.

In the present study line-by-line coding was used to label each line of data and to create a wide range of "initial codes". Line-by-line coding made the researcher keep close to the data and simultaneously think about the material in new ways. It subsequently helped the researcher to gain sufficient distance from her own, and the participants', taken-for-granted assumptions about the material, so that it could be viewed in a fresh manner. A list was compiled of 22 themes/categories that appeared frequently during initial coding:

1. Fear of disclosure and shame;
2. Stigmatisation;
3. Guilt feelings because of infecting others;
4. Fear of infecting others;
5. Feelings of blame and anger towards the person responsible for infecting her;
6. Concerns regarding physical deterioration and illness symptoms;

7. Personal losses and changes (physical, psychological, and social);
8. Concerns and fears regarding death and dying;
9. Suicidal thoughts and thoughts of death as a means of being rescued or set free from suffering;
10. Uncertainty regarding duration of life, recovery, and the future;
11. Concerns and needs regarding religion, faith, and prayer;
12. Concerns regarding children;
13. Concerns regarding her partner's illness;
14. Lack of and/or need for support and acceptance;
15. Effect of HIV/AIDS on daily functioning;
16. Loneliness and isolation;
17. Concerns regarding coping with the illness and consequences;
18. Alcohol abuse and consequences;
19. Relationship problems and concerns;
20. Concerns regarding intimate and sexual relationship;
21. Financial problems and concerns;
22. Concerns regarding housing and living conditions.

This list of 22 categories was then used in a second round of focused coding, during which all the interviews were coded again in a more workable and purposeful coding process. Because focused coding is less open-ended and more directed, selective and conceptual than line-by-line coding, it permitted the researcher to create and to test different categories for capturing data. The 22 categories were adapted and changed, with the researcher focusing on the categories that emerged most prominently during data analysis. Willig (2001) described this process as moving from low-level categories to higher-order analytic categories. According to her, focused coding assists the researcher to arrange categories in a meaningful way, with some categories forming the "core" and others the "periphery". Charmaz (1995) stated that categories may be *in vivo* codes that are taken directly from the respondents' discourse or they may represent the researcher's theoretical or substantive definition of what is happening in the data (p.41). In the present study

both of these methods were used to analyse the data. A list was then compiled of 10 key categories and related themes/codes describing each category:

1. HIV-diagnosis and initial reaction:
   Shock, sadness, hopelessness and despair, blame, guilt;
2. Stigmatisation and fear of disclosure:
   Fear of rejection and losses, problems with trust;
3. Clinical issues:
   Distress regarding physical condition, illness symptoms, and appearance;
4. Psychosocial losses:
   Loss of self and self-worth, loss of woman- and motherhood, loss of relationships, loss of being productive, loss of social life;
5. Psychological distress:
   Loneliness (emotional and social isolation), anxieties regarding lifespan and future, anxieties about treatment and recovery, anxieties regarding death and suffering;
6. Depression:
   Symptoms of depression, suicide ideation, death as deliverance;
7. Relationship concerns:
   Effect of illness on relationships and concerns regarding partner, children, parents, and other family members;
8. Need for social support and acceptance;
9. Coping strategies:
   Secrecy, alcohol abuse, faith and prayer, hope, children, socialising, social support, living healthily;
10. Concerns regarding socio-economic issues:
    Financial problems, work, housing and living conditions.

The researcher attempted to build and to clarify the key categories by examining all the data relating to them and by identifying the variations within them and between other categories. The above key categories and themes/codes served as the basis for the discussion of the qualitative results in Chapter 5.

4.5.2.5 Memo-writing

Memo-writing is the intermediate step between coding and the first draft of the completed analysis (Charmaz, 2000). According to Charmaz (2000), this step helps to spark the researcher's thinking and encourages him or her to reflect and view the data and codes in a new light. Charmaz (2000) stated that memo-writing helps researchers 1) to grapple with ideas about the data; 2) to set an analytic course; 3) to refine categories; 4) to define the relationships among various categories; and 5) to gain a sense of confidence and competence in their ability to analyse data. According to Willig (2001), memo-writing means writing definitions of categories and justifying labels selected for them, tracing their developing relationship with one another, and keeping record of the progressive integration of higher- and lower-level categories. In the present study memo-writing was done after the initial coding of the interviews and continued till the dissertation was completed.

4.5.2.6 Writing up the analysis

Charmaz (2000) stated that the analysis of qualitative data does not end when the grounded theorist has developed a theoretical framework; it continues into the writing. According to Charmaz (1990; 1995), the researcher should provide enough raw data in the text to illustrate the relationship between the data and the analysis. Furthermore, in the written analysis the researcher should make theoretical relationships clear. The verbatim material is only used when it highlights these theoretical relationships. Charmaz (2000) encouraged the use of simple language and straightforward ideas, which makes theory readable and understandable.

Charmaz (1990) emphasised that the relevant literature should only be consulted for comparison after the conceptual analysis of the data has been developed. Willig (2001) affirmed that since Grounded Theory research aims to develop new, contextualised theories, a review of existing literature has to be undertaken with caution; therefore it is essential for the researcher to keep a certain distance from such literature. "The Grounded

Theory study reported must not be seen as an extention of, or a test or, an existing theory" (Willig, 2001, p.39). Glaser (cited in Charmaz, 1990) pointed out that "grounded theorists must do their own analytic work; if they borrow concepts from the literature, then they should ensure that these concepts merit a place in their analysis" (p.1163). According to Charmaz (1990), the grounded nature of this research strategy is threefold: 1) researchers attend closely to the data (which amounts to discoveries for them when they study new topics or areas); 2) their theoretical analyses build directly on their interpretations of processes within those data; and 3) they must finally compare their analyses with the existing literature and theory.

In the Grounded Theory analysis in Chapter 5, the focus is on the core concept "illness experience" as well as on how other concepts are related to the core concept. Verbatim material is used to keep the human story in the forefront of the reader's mind, as well as to explain and illustrate points made by the researcher.

In the present study the relevant literature on HIV/AIDS and women was consulted for comparison after the researcher had developed the conceptual analysis of the data. Thus, significant literature and research are cited, discussed, and compared with the analysis of the present study in Chapter 5. However, a brief review of the psychological literature on the illness experience of HIV-infected women in the field of Psychology is presented as Addendum A (p.313).

4.5.3 Critique of Grounded Theory

The most widely raised criticism of Grounded Theory is that it subscribes to a positivist epistemology and that it evades questions of reflexivity (Annels, 2001; Charmaz, 1990; Willig, 2001). Willig (2001) stated that Grounded Theory works with induction, whereby observations give rise to new ideas. According to her one of the problems associated with induction is that it pays inadequate attention to the role of the researcher, because it is assumed that the data speaks for itself. Nevertheless, as critics of positivism have argued

persuasively, all observations are made from a particular perspective, thus they have a specific point of view. Willig (2001) explained that whatever comes to light from a field through observation depends upon the observer's position within it; consequently, whatever emerges from the analysis of a set of data is theoretically informed because all analysis is essentially guided by the questions asked by the researcher. Therefore, Grounded Theory has been criticised for not attending adequately to questions of reflexivity (Willig, 2001).

According to Willig (2001), social-constructionist versions of Grounded Theory (for example Charmaz 1990, 1995) attend to these concerns and endeavour to develop reflexive Grounded Theory. Charmaz (2000) stated that debates had resulted in reassessments of Grounded Theory. According to her, a constructivist Grounded Theory recognises that the researcher creates the data and resulting analysis through interaction with the research participant. She emphasised that from this perspective data does not provide a window on reality, but the discovered reality arises from the interactive process and its temporal, cultural, and structural contexts. Researcher and subjects create that interaction and consequently give meaning to it. According to Charmaz (1990), most Grounded Theory researchers have developed conceptual analyses of lived experiences instead of constructing tightly framed theories that generate hypotheses and make specific predictions. However, she emphasised that Grounded Theory methods do provide the tools for theory development and do offer psychologists the means for reviewing psychological theory.

According to Lesch (2000), a possible reason for this shortage of theory in much of the published Grounded Theory research lies in the fact that Grounded Theory entails a very extensive process and it may well take several months to refine the theory around the core category. She further stated that since many researchers work within specific time limits, it is likely that studies are published before the point of interpretative saturation. For this reason many studies may reflect merely the first phase of the theory-developing process. In the present study it was endeavoured to develop theory and go beyond just the development of analytic concepts.

Grounded Theory is also strongly criticised for splitting up, and thereby decontextualising, the data. Furthermore, it is criticised for not taking language seriously enough. In the application of Social-constructionist Grounded Theory in the present research study, the main focus of the analysis was on how this specific group of mothers constructed meaning of their experience of being HIV-infected; therefore extensive verbatim material was used to reflect the real experiences of these women in their own language. These excerpts and citations were also presented to illustrate and explain theoretical arguments and findings.

4.6 Reliability and validity

Proponents of quantitative research frequently question the validity and reliability of qualitative research findings. According to Banister et al. (1995), with a qualitative approach knowledge is accepted as constructed, as one version of reality, a representation rather than a reproduction. These writers explained that there is also a focus on critical examination on a number of levels, in the form of researcher reflection on both the process and experience of doing the research and the ways in which the findings were constructed. Qualitative research also incorporates an expectation of change in all involved in the research, including the researcher (Banister et al., 1995). Willig (2001) stated that qualitative research explores a particular, most probably unique, phenomenon or experience in great detail and does not aim to measure a specific attribute in huge numbers of people. Because of this the concept of reliability is not appropriate for this kind of research, and therefore qualitative researchers are less concerned about reliability (Banister et al., 1995; Willig, 2001). The traditional criterion for reliability is consistency, the extent to which the measurement device or test produces the same approximate results when utilised repeatedly under similar conditions (Reber, cited in Banister et al., 1994; Willig, 2001). Banister et al. (1995) pointed out that replication in qualitative research has more to do with reinterpreting the findings from a different angle or exploring the same issues in different contexts rather than expecting or wanting consistent accounts.

Another important aspect in the process of data collection and interpretation is validity. Willig (2001) defined validity as the degree to which research describes, measures or explains what it aims to describe, measure or explain. Janesick (2000) stated that validity in qualitative research has to do with description and explanation and whether or not the explanation fits the description. Thus, it is basically inquiring whether the explanation is credible. She explained further that qualitative researchers do not claim that there is only one way of interpreting an event and accept that there is also no one "correct" interpretation. According to Lincoln and Guba (2000), one of the issues around validity is the fusion between method and interpretation. Richardson (cited in Lincoln & Guba, 2000) stated that the postmodern thinkers' claim that no method can deliver on ultimate truth, the more so the bigger their claims to delivering on truth. Thus, although one might argue that some methods are more suited than others for conducting research on human construction of social realities, no one could argue that a single method, or compilation of methods, is the royal road to ultimate knowledge (Lincoln & Guba, 2000). Banister et al. (1995) argued that validity in qualitative research is focused on personal and interpersonal qualities, rather than method. It is "knowledge in process, which is tied up with a particular knower" (Reason et al., cited in Banister et al., 1995, p.152).

Lincoln and Guba (2000) pointed out that the interpretations of human experiences are themselves the subject of debate. These writers explained that traditional social scientists would like to see human phenomena restricted to those social experiences from which generalisations may be drawn. Conversely, new-paradigm researchers are progressively more concerned with the single experience, the individual crisis, and the moment of discovery, and with the greatest threat to conventional objectivity, feeling and emotion. "Social scientists concerned with the expansion of what count as social data rely increasingly on the experiential, the embodied, the emotive qualities of human experience that contribute the narrative quality to a life" (Lincoln & Guba, 2000, p.179).

According to Willig (2001), much qualitative data collection takes place in real-life locations and therefore it is not necessary to extrapolate from a non-natural setting to the real world, which means that such studies have higher ecological validity. She pointed out

further that reflexivity ensures that the research process as a whole is examined throughout and that the researcher constantly reviews his or her own role in the research. According to her, this discourages impositions of meaning by the researcher and thus advances validity.

Guba and Lincoln (cited in Lincoln & Guba, 2000) proposed criteria for judging the processes and outcomes of constructivist research studies, rather than the application of certain methods. These writers described five potential outcomes of a social-constructionist inquiry, rooted in the proverbs and assumptions of the constructivist paradigm: "Those authenticity criteria – so called because we believed them to be hallmarks of authentic, trustworthy, rigorous, or 'valid' constructivist or phenomenological inquiry – were fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity" (Guba et al., cited in Lincoln & Guba, 2000, p.180).

Fairness was thought to be a quality of balance, through which all participant views, perceptions, claims, concerns, and voices should be evident in the text (Guba et al., cited in Lincoln & Guba, 2000). Exclusion of participant or stakeholder voices reflects a form of bias that is not linked to the concerns of objectivity that flow from positivist inquiry, but is reflective of inquirer blindness or subjectivity. These writers defined fairness as deliberate efforts to prevent marginalisation, to act affirmatively with respect to inclusion, and to act with vigour to make certain that all voices in the inquiry effort had a chance to be represented in any texts and to have their stories treated fairly and with balance (Guba et al., cited in Lincoln & Guba, 2000).

Ontological and educative authenticity were chosen as criteria for determining an increased level of awareness, in the first instance, by individual research participants and, in the second, by individuals regarding those people with whom they come into contact for some social or organisational purpose (Guba et al., cited in Lincoln & Guba, 2000). According to Guba et al. (cited in Lincoln & Guba, 2000), these criteria are reflective of Schwandt's proposed "social inquiry as practical philosophy", with its aim to enhance or cultivate critical intelligence in parties to the research encounter (p.179). Critical intelligence is

defined as “the capacity to engage in moral critique” (Guba, cited in Lincoln & Guba, 2000, p.179). Willig (2001) stated that qualitative studies should aim to ensure that participants are free to challenge and, if necessary, correct the researcher’s assumptions about meanings investigated by the research. Consequently, participants should be given the opportunity to verbalise their thoughts and feelings regarding the research questions and outcomes of the study.

Lincoln and Guba (2000) stated that catalytic and tactical authenticities refer to the ability of a given inquiry to prompt, first, action on the part of research participants, and second, the involvement of the researcher in training participants in specific forms of social and political action if participants desire such training. According to these writers, it is here that constructivist inquiry practice begins to resemble forms of critical theorist action, action research, or “participants for positive social change” and forms of emancipatory community action.

During the present research study the researcher aspired to uphold the authenticity criterion of fairness by listening to each participant attentively during the interview and giving voice to her specific and personal experiences, concerns and needs. This is reflected in the text of the next two chapters. Ontological and educative authenticities were aspired to by making the participants aware of the importance of these concerns and needs. The last two criteria, catalytic authenticity and tactical authenticity, were aspired to by referring participants for social support and medical help, as well as through the researcher’s ongoing psychosocial support and counselling of the participants. The goal of compiling guidelines in a brochure for health workers and distributing them to appropriate health services could also benefit the participants as well as women with HIV/AIDS in general.

4.6.1 Triangulation

Triangulation refers to the use of various vantage points in the research process and consequently allows for flexibility and a diversity of experience (Banister et al., 1995). According to Flick (cited in Willig, 2001), “triangulation is a way of enriching and completing knowledge and transgressing the epistemological potentials of the individual method” (p.76). Banister et al. (1995) stated that, traditionally, one method of data collection and analysis was seen as sufficient and multi-method studies were rare. According to Banister et al. (1995), we need to acknowledge that all researchers, perspectives and methods are value laden, biased, and limited as well as explicated by their frameworks, specific focus and blind spots. They stated further that triangulation makes use of combinations of methods, investigators or perspectives, consequently facilitating richer and potentially more valid interpretations.

4.6.1.1 Method triangulation

Fine, Weis, Weseen & Wong (2000) emphasised that the use of multiple methods, or triangulation, in qualitative research reflects an attempt to secure an in-depth understanding of the phenomena in question. According to these writers the research issues of concern and the questions being asked would direct the particular combinations employed.

According to Straus et al. (1998), the researcher’s own preference for and familiarity and ease with a research method would inevitably also influence choices. They stated further that the purpose of the research and the nature of questions asked would often determine the method/s; a researcher ultimately has to work with those methods with which he or she feels most comfortable. Strauss and Corbin (1998) emphasised that to build well-developed, integrated and comprehensive theory, a researcher should make use of every method at his or her disposal, keeping in mind that a true interplay of methods is necessary. Silverman (cited in Willig, 2001) argued that triangulation of methods may lead to discounting the role of context in the construction of meaning. Willig (2001) explained that when a researcher

makes use of a diversity of methods, especially methods that are not epistemologically compatible, he or she has to combine insights gained from different analytic approaches. This may cause the researcher to focus on resolving tensions and contradictions and, in so doing, to lose sight of context-specific aspects of the data. According to Willig (2001), it is essential that methods of data collection and analysis used in triangulation are suitable to the research question asked as well as epistemologically well-matched with one another.

As discussed earlier in this chapter, for this study an in-depth qualitative interview was chosen as the primary method for data collection and analysis (Addendum C1, Psychosocial items, pp.362-363). Additional data concerning the participants' health status as well as biographical factors were gained by including a quantitative questionnaire at the start of the interview schedule (Addendum C1, Socio-demographic items, p.361, Health-related items, p.362). These variables were considered important for understanding illness-related experiences. The research methods chosen for the present study secured a thorough understanding of the research subject.

4.6.1.2 Investigator triangulation

Investigator triangulation means that more than one researcher, preferably from different disciplines or perspectives, or adopting different roles, are employed in carrying out the research. The aim is to obtain several viewpoints to enrich the developing theory (Banister et al., 1995; Willig, 2001). According to Banister et al. (1995), there are clear links between investigator triangulation and working in a multidisciplinary team.

In the present study the researcher discussed the research methods and material with her promoter who is a clinical psychologist, trained as a psychodynamic therapist. The researcher also discussed the interviews, analysis and results with her promoter and the director of Stellenbosch Hospice, who is a trained psychologist, and has been working with terminally ill people for many years. Although the researcher did not give detailed feedback to all the participants, she did discuss specific distresses and concerns with most

of them in follow-up counselling and support sessions. Counselling and support were offered to every participant during the closing stage of the interview; however, a few of the participants did not make use of this proposition.

4.6.1.3 Theoretical triangulation

Theoretical triangulation embraces multi-theories and breaks down the barriers that inevitably bound an explanation which relies on one theory (Banister et al., 1995). Theoretical triangulation is compatible with a social-constructionist approach and recognises complexity and diversity and that multiple realities exist. Although social constructionism was applied as the metatheory and epistemological basis for this study, different theories for understanding illness and health, as discussed in Chapter 3, influenced the viewpoint of social constructionism.

According to Banister et al. (1995), our challenges as qualitative researchers are “to access and represent adequately the research phenomena, to make certain that we act responsibly and engage in effective practices in our search for useful and illuminating ways to construct reality” (p.157). In this section certain ways and processes to increase validity were discussed. It is important to remember, however, that totally valid research, which captures and represents an absolutely “truthful” view of reality, is not deemed to be possible within a social-constructionist framework (Banister et al., 1995). Reason et al. (cited in Banister et al., 1995) stated that validity in qualitative research is connected with a particular inquirer or researcher. Therefore, the researcher can only go as far as explaining and clarifying the research process, and from that point on the knowledgeable reader must decide on the credibility of the research.

4.7 Reflexivity

Reflexivity requires a realisation of the researcher's contribution to the construction of meanings throughout the research process, and recognition of the impossibility of standing "outside of" one's subject matter while conducting research (Willig, 2001). Guba et al. (cited in Lincoln & Guba, 2000) stated:

> Reflexivity is the process of reflecting critically on the self as researcher, the 'human as instrument'. It is a conscious experiencing of the self as both inquirer and respondent, as teacher and learner, as the one coming to know the self within the processes of research itself. (p.183)

According to Lincoln and Guba (2000), reflexivity forces us to come to terms not only with our choice of research problem and with those with whom we engage in the research process, but also with ourselves and with the multiple identities that represent the fluid self in the research setting. Reinharz (cited in Lincoln & Guba, 2000) argued that we not only bring the self to the research field, we also create the self in the field. She suggested that although we all have many selves we bring with us, those selves fall into three categories: research-based selves, the selves that historically, socially and personally create our standpoints, and situationally created selves. Each of those selves comes into play in the research setting and, consequently, has a distinctive voice.

Lincoln and Guba (2000) stated that reflexivity demands that we question each of our selves regarding the ways in which research efforts are shaped and staged around the contradictions and paradoxes that form our lives. Lincoln and Guba (2000) emphasised further that the researcher must question herself regarding how these binaries and paradoxes shape not only the identities called forth in the research field and later in the discovery processes of writing, but also in the researcher's interactions with respondents, namely who she becomes to them in the process of becoming herself. Therefore, reflexivity urges us to explore the ways in which our involvement with a particular study shapes, influences, acts upon and informs such research (Nightingale et al., cited in Willig, 2001).

Banister et al. (1995) identified two concepts of reflexivity, personal reflexivity and functional reflexivity. The concept of personal reflexivity requires that the researcher should acknowledge and disclose who she is and how her personal interests, values, experiences, beliefs, political commitments, wider aim in life, and social identities has influenced the research process throughout (Banister et al., 1995; Willig, 2001). Functional reflexivity, on the other hand, entails that the researcher continuously appraises the research process to reveal how she has influenced and shaped the research process (Banister et al., 1995). Willig (2001) discussed a third type of reflexivity, namely epistemological reflexivity, which requires us to ruminate upon the assumptions, about the world and about knowledge, that we have made in the course of the research, and which helps us to think about the consequences of such assumptions for the research and its findings.

Willig (2001) pointed out that Grounded Theory has been criticised by quantitative researchers for not addressing questions of reflexivity sufficiently. Therefore, Pidgeon and Henwood (1997) recommended that Grounded Theory researchers document, cautiously and in detail, each stage of the research process. According to these writers such records enhance reflexivity throughout the research process and reveal the ways in which the researcher's assumptions, values, sampling decisions, analytic technique, interpretations of context, and so forth have shaped the research.

To satisfy the request for personal and functional reflexivity, the researcher included the following paragraphs that contain and reflect some of her personal values, interests and experiences which had an effect on the selection of the research topic and the research process (inter alia, the researcher's input as co-constructor of the research interviews and interpreter of the interviews) and, ultimately, on the findings of this study.

"I am a 43-year-old white Afrikaans-speaking, single mother of two young children. I run a household as well as a private clinical psychology practice from home. Most of my school years were spent in Somerset West, a town in the Western Cape. I had a Christian-national-based

school education and a Calvinistic upbringing. From my teenage years I questioned the division the apartheid policy imposed on people from other races than 'white'. This concern grew stronger when I went to the University of Stellenbosch to study for a four-year degree in Home Economics. Probably different from most other white students, I had close friends in Cloetesville, a Coloured suburb just outside central Stellenbosch, whom I visited regularly. During that time, the early eighties, it was an area designated for Coloured people under the Group Areas Act. By chance, many of the participants in the present study were interviewed by the researcher at the Cloetesville clinic, as they resided in this area. My main subjects in my final years of Home Economics were community development, adult education, sub-economic housing and nutrition. After completing my four-year degree, I worked as community coordinator for the City of Cape Town in Mitchell's Plain and other sub-economic Coloured housing schemes. The work mostly entailed assessing the social needs of the community and planning programmes to address these needs. Being involved in assessing people's needs for housing and community services, I did my Master's degree in Home Economics on this topic.

I also worked for the National Cancer Association, where I was responsible for the planning and presenting of awareness programmes, which generally promoted healthy living and the early detection of cancer. Working in disadvantaged communities for many years and being emotionally involved with people who experienced a lot of suffering, as well as my own personal interest in the psychological functioning and needs of disadvantaged people, encouraged me to pursue psychology as field of study. Throughout my years of study I worked for Stellenbosch Hospice as AIDS and bereavement counsellor, with terminally ill patients and their families. As the AIDS crisis escalated, people with HIV/AIDS were increasingly referred to Stellenbosch Hospice and consequently I became more involved with these patients. The majority of them were women from disadvantaged communities. As has been mentioned in this chapter, my research topic evolved from these experiences as well as my own concern and aspiration to make a contribution to support these women.

Because of the nature of my work as counsellor and therapist, I preferred a qualitative research method and felt familiar and comfortable using in-depth interviews for data collection. I believe that a sensitive and serious topic such as HIV/AIDS can only be truly studied thoroughly if a person is given the opportunity to speak freely and openly about his or her experience of such a condition within a safe environment. During my years of working in disadvantaged communities, it was clear that cultural, political, and socio-economic factors had a very important effect on how these people

experienced daily life as well as distressing life events and situations. I believe that social constructionism was therefore the appropriate theoretical framework of choice for this study. Throughout the research process, especially during the analysis of the data, I attempted to keep the specific and unique cultural and social contexts, within which the women participants experienced their illness, in the forefront of my mind.

My work experience and training in psychology influenced my choice of research question as well as the categories and themes in the data on which I focused. I focused primarily on psychosocial issues and distresses experienced by these women. Clinical/physical issues were included and analysed because of the important effect of physical illness symptoms on HIV-infected women's psychosocial functioning, and vice versa. I acknowledge that my own values, personal interests, work experience and field of study influenced and shaped the analysis of the data and the research process throughout. However, the discourses discovered reflect the participants' personal constructions of the illness experience. Throughout the research process I attempted to stay as close as possible to the real experiences of these women, and consciously tried to keep my own pre-conceived ideas and beliefs about women/mothers, illness and suffering in the background.

For me personally it was a tremendous privilege to meet these women, to interact with them and to be able to listen to their stories, which were filled with suffering, pain and hardships, but also with remarkable courage, resilience and hope. I hope that the text will enhance the reader's insight into and understanding of the experiences of this particular group of HIV-infected women."

4.8 Consultation and ethical responsibilities

Banister et al. (1995) stated that researchers should be cognisant of the ethical implications for participants during the process of research, from planning through to outcome and sometimes even beyond. They emphasised further, "that participants need to be protected from harm; their psychological wellbeing, health, values and dignity need to be preserved at all times" (Banister et al., 1995, p.152).

Christians (2000) summarised the four most important codes of ethics or guidelines for directing an inductive research study. Firstly, subjects or participants have the right to be

informed about the nature and consequences of the research study in which they are involved. Proper respect for human freedom generally includes two necessary conditions. Subjects must agree voluntarily to participate, that is, without physical or psychological coercion. In addition, their agreement must be based on full and open information (Christians, 2000, p.138).

The second guideline is to oppose any form of deception. The straightforward application of this principle suggests that researchers design research studies free of active dishonesty. According to Christians (2000) and Willig (2001), within both psychology and medicine some information cannot be obtained without at least deception by omission. The standard resolution for this dilemma is to permit a modicum of deception when there are explicitly utilitarian reasons for doing so.

The third guideline is ensuring privacy and confidentiality (Christians, 2000; Kvale, 1996; Willig, 2001). Codes of ethics insist on safeguards to protect people's identities and those of the research locations. Confidentiality must be assured as the primary safeguard against unwanted exposure. All personal data ought to be secured or concealed and made public only behind a shield of anonymity. Professional etiquette uniformly concurs that no one deserves harm or embarrassment as a result of insensitive research practices (Christians, 2000).

Fourthly, ensuring that data are accurate is a fundamental principle in social science codes as well. Fabrications, deceptive materials, exclusions, and set-ups are both non-scientific and unethical. "Data that are internally and externally valid are the coin of the realm, experimentally and morally" (Christians, 2000, p.140).

Willig (2001) emphasised the importance of informed consent, opposing deception, and ensuring confidentiality when conducting qualitative research. However, as ethical considerations she also included the right of a participant to withdraw from a study without fear of being penalised and the opportunity for debriefing after data collection. In a study such as the present research, participants could also be referred to appropriate

organisations or health professionals for support, care and help if they had problems that needed attention. According to Willig (2001), the researcher should make sure that, after data collection, participants are updated about the full aims of the research and, if possible, have access to any publications arising from the study they participated in.

The U.S. National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research put forward three principles, constituting the moral standards for research involving human subjects: respect for persons, beneficence, and justice. The principle of justice insists on fair distribution of both the benefits and burdens of research. According to Christians (2000), an injustice occurs when some groups (such as welfare recipients, the institutionalised or particular ethnic minorities) are overused as research subjects because of easy manipulation or their availability. Banister et al. (1995) emphasised that when participants come from a different ethnic, cultural, social or gender group, researchers need to discuss the research with a range of people from the appropriate group(s) in order to gain information and advice.

Ethical issues are also of the utmost importance when sensitive subjects or phenomena are studied, such as people with life-threatening or chronic illnesses. This is even more true with HIV/AIDS because of the extreme stigma attached to the illness. The University of Stellenbosch's ethical guidelines necessitate that where people or their behaviour is the focal point of research, "their right to decent treatment should be respected and in particular their right to privacy, their right to confidentiality of personal information, their right to informed consent and their right to the minimisation of risks to which people could be exposed in the research process" (University of Stellenbosch, 1998).

In the present research study, each participant signed an informed-consent form (see Addendum B, p.359). This was done after the researcher had thoroughly explained and discussed the objectives of the present study as well as the research procedure and process with the participant. In these informed-consent forms the following issues were highlighted:

- Credentials and work status of the researcher;
- The goal of the research;

- Explanation of the interview procedure (duration, place, time, recording of interview);
- The personal and sensitive nature of certain questions;
- Respondent's right to discontinue participation at any stage of the interview for any reason;
- Respondent's right to request that the researcher destroy all personal data concerning her;
- Respondent's right to refuse to answer any particular question/s during the interview;
- Confidentiality and specific measures to guarantee confidentiality for the duration of the research (from data collection to dissemination of information);
- The availability of resources (counselling, social and medical services) should the respondent express the need to be referred.

To ensure confidentiality and anonymity each participant was asked to choose a pseudonym of her liking, which was used throughout the taped interview and on all written documentation subsequently. Consultations with all relevant parties were conducted during the research process, to ensure that the research objectives were conveyed and all persons concerned could benefit from the study. The researcher hopes that the outcome of the research will be of benefit to the specific Coloured community, but also to many other low-income mothers with HIV/AIDS in the Western Cape as well as in the rest of South Africa. One of the aims of the research is to provide guidelines for health workers (professional and lay workers) in assisting and supporting HIV-infected low-income mothers based on their primary psychosocial needs and concerns. It can therefore be anticipated that the benefits of the research outweigh the possible discomfort experienced by mothers with HIV/AIDS when asked about their illness. The researcher's personal experience was that the participants welcomed and appreciated the opportunity to discuss their illness with an attentive person; because of the stigmatisation attached to the illness, they generally felt rejected and alone. Many of the participants saw the researcher for psychological support and counselling after the interview sessions and some joined the support group at Stellenbosch Provincial Hospital, which the researcher had initiated for women/mothers living with HIV/AIDS residing in the Stellenbosch area. Those in need of social aid were referred to the appropriate organisations or state departments (inter alia for disability

grants). Participants who experienced serious physical deterioration and illness symptoms were referred to the Stellenbosch Hospice for medical care.

In this chapter the research methodology was explained and discussed. The data obtained from the semi-structured, in-depth qualitative interviews, focusing on psychosocial issues and the mental health needs of the participants, will be presented and discussed in the next chapter.

CHAPTER 5

Grounded Theory analysis

In this chapter the researcher attempted to gain an understanding of how a specific group of HIV-infected mothers constructed meaning of their experience of being HIV-infected. By starting with data from the lived experience of the research participants, the researcher was able to focus from the beginning on how they construct their worlds. Grounded theorists aspire to create theoretical categories from the research data and then analyse relationships between key categories (Charmaz, 1990; 1995; 2000). According to the Grounded Theory method, the key categories explain and conceptualise 1) the data, 2) common-sense understandings of these data, and 3) other theoretical interpretations (Charmaz, 1990). Through the analysis of the present data several key and subcategories were identified. The key categories are listed in Chapter 4, section 4.5.2.4.

Charmaz (1990) stated that the nature of the grounded research strategy is threefold:

1. Researchers attend closely to the data (which amounts to discoveries for them when they study new topics and arenas);
2. Their theoretical analyses build directly on their interpretations of processes within those data;
3. They must ultimately compare their analyses with the existing literature and theory.

Through writing and rewriting this chapter, the researcher aimed to reveal the most important outcomes and arguments regarding the illness experience of the participants, provide a context for these findings, make comparisons with the relevant literature, critically examine the categories and concepts, and present the data clearly (Charmaz, 2000; 1995). In the following sections the different key and subcategories of the illness experience of these HIV-infected women are presented and discussed. Also, as the Grounded Theory analysis progressed it became clear that there were larger discourses that informed these categories. There will thus be a systematic attempt to highlight such

discourses in the summary of each section. In other words, the researcher will also focus on how the participants seemed to make sense of their worlds in general and how such coherent and context-specific systems of meaning-making (discourses) impacted on their illness experience.

It is important to make a few comments about the use of excerpts and citations from the research interviews. With the researcher applying Social-constructionist Grounded Theory, the main focus of the analysis was on how this specific group of mothers constructed meaning of their experience of being HIV-infected, therefore extended verbatim material was used to keep the human story and the real experiences of these women in the forefront of the reader's mind. These excerpts and citations were also presented to exemplify and explain theoretical arguments and findings. Although citations were kept as concise as possible, it was important to make clear the context within which participants made statements. Citations are therefore often lengthy. Furthermore, the reader should keep in mind that 11 interviews of approximately two hours each produced a vast amount of data. Based on Grounded Theory principles, the analysis following did not aim to reproduce all of what had been said by the participants, but rather to present the data that underlie the theoretical arguments that were finally developed.

The citations of the women were professionally translated from Afrikaans, their mother tongue, to English so that their own stories and experiences could be understood and appreciated by diverse readers. In the process of translating the quotes from Afrikaans into English, a great deal of the meaning of the idiomatic Afrikaans words was lost. It is generally accepted that it is almost impossible through translation to portray precisely the authentic meaning of all words and phrases in a different language, especially when the original language is used in an inimitable way by a specific cultural group. Therefore, the Afrikaans texts were also included, because of the unique and descriptive way these women portrayed their experiences in their own language. A citation is first presented in English, followed directly by the original Afrikaans version. In these excerpts and citations the pseudonym of each participant is used, as has been done in Chapter 4, according to the ethical codes for privacy, anonymity and confidentiality.

The illness experience of the participants can be divided into two stages, finding out about the illness and living with the illness. As the participants talked about their illness experiences they also implicitly talked about their assumptions about womanhood and motherhood. These gendered discourses will also be highlighted throughout this chapter. Section 1 of this chapter focuses on the women's experiences when they heard about their diagnosis and Section 2 of this chapter, and onwards, focuses on their experiences of living with the illness on a daily basis. The next section will commence by focusing on the initial reaction of the women participants at the time they were given their HIV-positive test results.

5.1 HIV-diagnosis and initial reaction

When the participants in the present study were asked to tell about the first time they heard that they were HIV-positive, their accounts seemed remarkably detailed and clear, even though for the majority the time since diagnosis was 12 months or more. The emotions at the time of diagnosis most often described by these women were shock, sadness, hopelessness and despair. Blame, disappointment, anger and guilt were also mentioned by the participants as emotions experienced when they heard that they were HIV-positive. Almost all the participants reported that they were instantaneously concerned about their children's well-being should they as mothers fall ill or die. A great concern for all the participants at the time of diagnosis was the issue of disclosing or not disclosing their HIV-status to family members and/or friends.

5.1.1 Shock

The positive HIV-diagnosis was a sudden and unexpected experience of extreme surprise for all of the participants in the present study. The first emotion primarily experienced by the women when they received their positive diagnosis, was shock. Some of the participants narrated their feelings of shock and their reactions as follows:

"I went and he said my blood is um positive… I'm HIV-positive and my husband also had to come… and my husband also went for the blood tests and he tested my husband as well and my husband's were also positive. And um it was very hard for us and um as we got home that night … he didn't really talk about it, he was too shocked and me as well." (Ann)

"Ek het gegaan en hy het gesê my bloed is um positive… ek is HIV-positive en my man moet ook kom… en my man het ook gegaan vir bloedtoetse en hy het my man ook getoets en my man sinne was ook positive. En uh dit was baie swaar vir ons en uh die aand toe ons nou by die huis kom… hy het nie eintlik gepraat daaroor nie, hy was te geskok en ek myself ook". (Ann)

"I was greatly, terribly shocked to think I'm still young in life and now to be saddled with the virus." (Joeyce)

"Ek was groot vreeslik geskok gewees om te dink ek is nog jonk in die lewe en nou opgeskeep te sit met die virus." (Joeyce)

The behaviour and reactions triggered by the shock the participants experienced were frequently described as speechlessness, confusion, motionlessness or paralysis and numbness:

"But afterwards almost like someone who, I was quite confused. That sister still asked me if there's something you want to say and so. I just looked at her like someone who doesn't understand. I just looked at her. P (her male friend) talked, she talked, they asked me something. I didn't even concentrate on them any more, because the moment I heard… I was just there. Almost like someone who's retarded, quite feeble-minded I sat, like that I sat and sat and sat. I wasn't even interested in what was happening around me." (Maggie)

"Maar agterna amper soos een wat, ek was heel deurmekaar. Daai suster het nog vir my gevra is daar iets wat jy wil sê en so. Ek het hom net so gekyk soos iemand wat, wat nie verstaan nie. Ek het haar net so gekyk. P (haar mansvriend) het gepraat, sy het gepraat, hulle het vir my iets gevra. Ek het nie eers mee konsentrasie vir hulle gegee nie, want die oomblik toe ek hoor… was ek net daar. Amper soos iemand wat vertraag is, heel simpel so het ek gesit, so het ek gesit en gesit en gesit. Ek stel nie eers belang wat rondom my aangaan nie." (Maggie)

"I talked to my husband, why is it like this, then he said he also didn't know that he had HIV as well… I got a fright then I just sat dead quiet, sat looking at the doctors…" (Rosy)

"Ek het gepraat saam met my man, hoekom is dit dan nou so, toe sê hy hy het ook nie geweet nie dat hy ook HIV het nie… Ek het geskrik toe sit ek maar net dood stil, die dokters sit en aan kyk…" (Rosy)

Some of the participants used different words to describe their experience of shock. Elna explained her reaction as getting a "fright" (geskrik) and experiencing a sense of paralysis when she received the unexpected news of being HIV-positive:

"I couldn't move, I sat for a long time, the sister talked to me about it. I couldn't answer her, because she also asked me the same question, how do you feel. I told her, I don't know how to feel, because I've just received a shock. I didn't expect that it would happen to me, but… I don't know I just sat sat sat until I decided but she's got other appointments, I have to go home now." (Elna)

"Ek kon nie beweeg nie, ek het lank gesit, die suster het met my daaroor gepraat. Ek kon nie vir haar antwoord nie, want sy het ook dieselfde vraag gevra, hoe voel jy. Ek het vir haar gesê, ek weet nie hoe om te voel nie, want ek is nou net geskrik. Ek het nie verwag dit sal met my gebeur nie, maar… ek weet nie ek het net gesit gesit gesit tot ek besluit het maar sy het ander afsprake ek moet nou huistoe gaan." (Elna)

Maggie described her shock reaction to the news of being HIV-positive as feeling "very weak" (baie swak) and this most probably referred to an emotional and physical state of weakness. She also described a feeling of emptiness:

"At that moment I actually thought of nothing, actually thought of the sickness I have. And it was very hard for me to accept. I was very weak when I got the result, very weak." (Maggie)

"…op daai oomblik het ek eintlik aan niks gedink nie, eintlik gedink aan die siek wat ek het. En dit was vir my baie moeilik om te aanvaar. Ek was baie swak toe ek die uitslag gekry het, baie swak." (Maggie)

For certain participants the experience of shock triggered feelings of disbelief, fear, panic, confusion and going mad or losing control. Maggie described how the shock of hearing that she was HIV-positive was almost too much to bear:

"The first time I heard I was HIV+ I was very shocked, I was pushed down, I couldn't believe it, I didn't know something like this could happen. At first I wanted at first I wanted to tell them no man, you must be making a mistake. It can't be. It's not possible. I almost turned crazy…" (Maggie)

"Die eerste keer toe ek gehoor het ek is HIV+ was ek baie geskok, ek was terug gedruk, ek kon dit nie glo nie, ek het nie geweet so iets kan gebeur nie. Ek wou eers ek wou eers vir hulle gesê het, nee man maar julle maak seker 'n mistake. Dit kan nie wees nie. Dit is nie moontlik nie. Ek het amper mal geraak…" (Maggie)

Sylvie experienced feelings of disbelief and confusion, not knowing how to react to her diagnosis:

"And I just told him I called him by his name doctor and... and said you must tell me what uh just tell me it is so. He told me then it is so... and then he told me, it's the Hepatitis and HIV with the AIDS. It is it was terrible... I couldn't accept it, I didn't want to and I didn't know what to do." (Sylvie)

"En ek het net vir hom gesê ek het hom op die naam genoem dokter en... en gesê jy moet vir my sê wat uh sê net vir my dit is so. Hy't vir my gesê dan is dit ook so... en toe het hy vir my gesê, dis die Hepatitis en HIV met die AIDS. Dit is dit was verskriklik... ek kon dit nie aanvaar nie, ek wou nie en ek het nie geweet wat om te doen nie." (Sylvie)

Ann articulated a reaction of fright, which manifested in an almost instant suicidal impulse:

"I almost ran into a car across the road that day from fright when we heard the news for the first time. I mean we didn't expect it. And my husband hasn't actually ever talked about it. It was very hard to accept it at the time." (Ann)

"Ek het amper daai dag in 'n kar in gehardloop daar oor die pad van skrik toe ons nou die nuus hoor die eerste keer. Ek meen ons het dit nie verwag nie. En my man het nog nooit eintlik gepraat daaroor nie. Dit was maar baie swaar om dit te aanvaar daai tyd." (Ann)

The following narrations of Maggie and Hester demonstrate the total devastation they felt when they heard that they were HIV-positive. According to Maggie, HIV had an immediate and drastic altering effect on her physical and emotional self. The emotion described by Maggie is one of feeling "pushed down" (terug gedruk), which most probably means feeling disheartened and distressed:

"Look, it it wasn't something one expected. It comes to you suddenly and you you think perhaps you go there, you get, you haven't yet got the result. You go in there with a good heart and courage. But as soon as you get the result everything is in vain. You don't look the same any more, you don't feel the same any more and you you are pushed down, because the shock is too quick." (Maggie)

"Kyk dit dit was nie iets wat mens verwag nie. Dit kom skielik na jou toe en jy jy dink miskien jy gaan daarnatoe, jy kry, jy het nog nie die uitslag gekry nie. Jy gaan met 'n goeie hart en 'n goeie moed daarin. Maar sodra jy die uitslag kry is alles te vergeefs. Jy lyk nie meer dieselfde nie, jy voel nie meer dieselfde nie en jy jy is terug gedruk, want die skok is te gou." (Maggie)

Hester narrated how she physically collapsed and needed support when she heard that she was HIV-positive. For her the dreadful news was too much to bear at that given point in time. She verbalised the emotional and physical consequences of being HIV-positive, which contributed to her feelings of shock and despair, as follows:

"The time that the doctors told me you're HIV+, I fell apart. I cried, they had to come to me apart, the social worker had to come to me. They had to come and talk to me, they had to give me a sedative uh Elsa, because I took it too badly. Because I know it's a sickness that nobody wants and that will never be cured." (Hester)

"Die tyd toe die dokters vir my sê jy is HIV+, ek het inmekaar geval. Ek het ek het gehuil, hulle moes na my eenkant toe kom, die maatskaplike werkster moes na my toe kom. Hulle moes met my kom praat, hulle moes my 'n kalmeer middeltjie ingegee het uh Elsa, want ek het dit te groot opgevat. Want ek weet dit is 'n siek wat niemand wil hê nie en wat nooit sal gesond raak nie." (Hester)

The above data correlates well with other research studies on the experiences of women with HIV/AIDS. For instance, the women participating in the study conducted by Withell (2000) experienced the time of diagnosis as very traumatic. These participants described feeling shocked, going mad or being dumbstruck, especially when they felt physically healthy. Leenerts and Magilvy (2000) stated that fear and panic were common responses for women at the time of diagnosis and that many described it as traumatic. According to Herman (1992), a traumatic event is extraordinary, because it overwhelms the ordinary human adaptations to life. Unlike commonplace misfortunes, traumatic events generally involve threats to life or bodily integrity, or being exposed to the possibility of dying (Herman, 1992). She stated further that a traumatic event confronts a person with extreme feelings of helplessness, fear, loss of control, and threat of annihilation.

In the above citations of the participants in the present study, feelings and reactions of shock, fear, panic, going mad and being speechless, numb or paralysed were frequently mentioned. It can be argued that the participants' construction of an HIV-diagnosis was that of being extremely traumatised. These feelings and reactions seemed to be based on an assumption that HIV/AIDS is an incurable and deadly illness.

5.1.2 Sadness

In the present study the shock of a positive diagnosis was so traumatic for the participants that they were motionless or "paralysed", and these reactions were often accompanied by

sadness. Many of the participants narrated that they experienced feelings of intense sadness and distress when they heard that they were HIV-positive. Most of them cried because of these feelings of sadness and distress. The participants verbalised their feelings as follows:

"I went home, went to sit alone in the room, then we still stayed in a room... sat there alone and cried in my room. I was very upset that day..." (Ann)

"Ek het huis toe gegaan mos, alleen gaan sit in die kamer, toe bly ons nog op 'n kamer... in my kamer alleen daar gesit en huil. Ek was baie omgekrap daai dag..." (Ann)

"I went and the results were positive and I was very sad... I cried a little bit and I couldn't believe it." (Maggie)

"Ek het gegaan en die uitslae was positief en ek was baie hartseer... ek het so bietjie gehuil en ek kan dit nie geglo het nie." (Maggie)

"I had a terrible infection and went to the clinic... I then went there the next day and experienced that I was HIV-positive. I didn't know how to take it, I just sat, the tears ran of their own accord..." (Elna)

"Ek het 'n skrik 'n verskriklike infeksie gehad en het na die kliniek gegaan... ek is toe die dag daarna soontoe en ondervind dat ek HIV positief is. Ek weet nie hoe hoe om dit op te vang nie, ek het gesit, die trane het vanself geloop..." (Elna)

"Afterwards as we left, it bothered me and I didn't talk to my husband about it... Then he just said no, we must still talk about this thing, but I didn't give him an answer. I felt too bad, sad." (Rosy)

"Daarna wat ons mos nou loop, het dit my gepla en ek het nie gepraat saam met my man nie... Toe het hy net gesê nee ons moet nog praat oor die ding, maar ek het hom nie antwoord gegee nie. Ek het te sleg gevoel, hartseer." (Rosy)

"Then they took blood then I felt bad, because I didn't know. Then I came to the clinic and then sister C told me I have those things. Then I was sad about those things that I didn't have before, what the guy had done to me." (Bertha)

"Toe vat hulle bloed toe het ek mos nou sleg gevoel, toe weet ek ook mos nie. Toe kom ek kliniek toe en toe sê suster C vir my ek het nou daai goeters. Toe is ek nou hartseer vir daai goed wat ek nooit gehad het nie, wat die outjie aan my gedoen het." (Bertha)

At the time when Sonja and Nossie heard that they were HIV-positive, they also received the distressing news that their babies were infected with the virus as well. They described their feelings of utter sorrow as follows:

"I felt very sad, I felt very sad to think that I had that sickness… and um they told me that um my baby also had that kind of sickness and it was not nice to to think that I had that sickness…" (Sonja)
"Ek het baie hartseer gevoel, ek het baie hartseer gevoel om te dink dat ek daai siekte het… en um hulle het vir my gesê dat um my baby het ook daai soort siek en dit is nie meer lekker om om te dink dat ek daai siekte het nie…" (Sonja)

"The first time um the doctor told me I was HIV-positive, I felt very bad. I was very sad and I didn't feel like having anybody around me because there was a counsellor with me and when when she came to talk to me but then I couldn't talk and I just cried. I was very very sad…. But I was just in tears it was just I just cried. The tears just ran of their own accord and and I sat there next to my child and I just kept praying to the Lord. I asked the Lord I asked the Lord does the child now have (HIV), does she have to suffer like this? And and and why then me, why does he choose me that I have to suffer from a sickness, you understand?" (Nossie)
"Die eerste keer toe um die dokter vir my sê dat ek HIV positief is toe het ek baie sleg gevoel. Ek was baie hartseer en ek het gevoel ek wil niemand rondom my hê nie, want daar was nou 'n raadgeefster by my en toe toe sy met my kom praat, maar ek kon nie gepraat het nie ek het net gehuil. Ek was baie baie hartseer… Maar ek was net in trane dit was net ek het net gehuil. Die trane het net vanself geloop en ek het gesit daar by my kind en ek het net biddend gebly by die Here. Ek het vir die Here ek het vir die Here gevra het die kind dan nou (HIV), moet sy so ly? En en en hoekom dan ek, hoekom kies hy dan vir my dat ek aan 'n siek moet ly, verstaan?" (Nossie)

Although most of the participants revealed that they were Christians during the interviews, Nossie was the participant who spoke about and emphasised the importance of her Christian faith the most. Her above narration shows that she immediately turned to God for help after receiving the dreadful news of a positive diagnosis. Simultaneously she expressed her deep sadness and concern for her suffering child. It is clear that Nossie was experiencing ambivalent feelings towards God, asking for help but also questioning and arguing with God for letting them become victims of this illness.

In the literature it is emphasised that a terminal illness can challenge a person's relationship with God (Nieuwmeyer, 2002). Nieuwmeyer (2002) found that some of the Xhosa women participants in her study had experiences of their faith being challenged and had certain doubts about God's beneficence towards them. Ambivalent feelings, such as a

need for comfort and to be rescued by God as well as anger and disillusionment with God, are not unusual experiences for a woman when she or her loved one falls terminally ill.

It seems from the above narrations of the participants that an HIV-diagnosis is constructed as an experience of intense sadness and distress. According to many writers, depressive feelings such as sadness are often the first response that is likely to occur after an HIV-diagnosis (Hudson et al., 2003; Kaplan et al., 1997; Murphy et al., 2002). In the present study the participants' experiences of sadness were often accompanied by other depressive feelings, such as hopelessness and despair, as well as thoughts of death and suicide.

5.1.3 Hopelessness and despair

Feelings of hopelessness and despair were strong among the participants in the present study. Many of them believed that their feelings at the time of diagnosis would continue indefinitely and that there would never be hope. Maggie described her diagnosis as receiving a death sentence:

"I felt as if the shroud had now been thrown over me or anything like that but I was withdrawn, I was very down, I didn't feel like doing anything." (Maggie)

"Ek het gevoel of ek nou die doodskleed oor my gegooi is of enigiets soos dit maar ek was teruggetrokke, ek was baie af, ek het lus gevoel vir niks." (Maggie)

For Nossie, immediate thoughts of her and her baby daughter dying of AIDS triggered deep feelings of hopelessness, sorrow and despair:

"Yes, yes when they tested me and I was then HIV. I I phoned my pastor to tell but I tell him they say I have AIDS... And and I'm going to die and my child is lying here and we are going to die...And the doctor said the girl must bring me a cup of tea and the doctor still talked to me, but my thoughts were only with my child. My child is going to die and I'm going to die..." (Nossie).

"Ja, ja toe hulle vir my getoets het en ek is toe HIV. Ek ek bel my pastoor om te sê maar ek sê vir hom hulle sê ek het AIDS... En en ek gaan dood en my kind lê hierso en ons gaan dood... En die dokter het gesê die meisie moet vir my 'n koppie tee bring en die dokter het nog met my gesels, maar my gedagtes was net by my kind gewees. My kind gaan dood en ek gaan dood..." (Nossie)

"I was thinking now I'm going to die, because I I'd heard it's a serious illness, very serious illness, because they can't cure it. So I'm going to lose my child and then I'm also going to die. It was my was my saddest time, because I thought now I'm going to die. Because I didn't know how far the the the the virus already was in my body..." (Nossie)

"Ek het nog gedink nou gaan ek dood, want ek ek het gehoor dit is dis 'n kwaai siekte, baie kwaai siekte, want hulle kan dit nie genees nie. So ek gaan my kind verloor en dan gaan ek ook dood. Dit was my was my hartseerste tyd gewees, want ek het gedink nou gaan ek dood. Want ek weet nie hoe ver was die die die virus al in my liggaam nie..." (Nossie)

The fatality of an HIV-diagnosis, accompanied by extreme feelings of hopelessness and despair, led to 6 of the 11 women contemplating suicide. These participants verbalised their feelings and thoughts as follows:

"It was a great shock to me. I felt like someone who now wanted to take my life, because I didn't think I would get it..." (Maggie)

"Dit was vir my 'n groot skok. Ek het gevoel soos een wat nou my lewe wil vat, want ek het nie gedink ek sal dit kry nie..." (Maggie)

"I thought I rather wanted to go and stand in front of the train so the train would just kill me. I was thinking of doing that. It's also not something good to do, to commit a murder." (Joeyce)

"Ek het gedink ek wil liewerster voor die trein loop staan dat die trein my eenmaal dood ry. Toe dink ek dit. Dit is ook nie iets goeds om te doen nie, 'n moord te pleeg nie." (Joeyce)

"...then you don't feel like living oh well, I'll just wait for the results. How they feel about me (her family), if they don't want to accept it, then I'll just have to put an end to my life or things like that, but then I think again on the other hand it's not worth the trouble." (Elna)

"...dan het jy nie lus vir die lewe aag, ek gaan maar wag vir die uitslae. Hoe hulle (haar familie) oor my voel, as hulle dit nie wil aanvaar nie, dan moet ek maar 'n einde sit aan my lewe of dinge soos daai, maar dan dink ek weer aan die anderkant is nie die moeite werd nie." (Elna)

"It was for me like something that had been taken away from me. I just felt that I no longer needed to live, because what do I do with a little girl who is HIV and I'm I'm also like that and what will become of my other little boy. Elsa, it felt to me as if I should take my own life." (Hester)

"Dit was vir my soos iets wat van my weggeneem was. Ek het net gevoel dat ek het nie meer nodig om te lewe nie, want wat maak ek met 'n dogtertjie wat HIV is en ek is ek is ook so en wat gaan word van my ander seuntjie. Elsa dit het vir my gevoel ek moet my eie lewe neem." (Hester)

"I was very upset, I thought ooh, there is no cure for me… I wanted to kill myself." (Rosy)
"Ek was baie ontsteld gewees, ek het gedink oe daar is mos nou nie weer 'n cure vir my nie… Ek wou myself doodgemaak het." (Rosy)

Sonja was the only participant who actually attempted suicide, but was rescued by a passer-by. She was also the only one that contemplated killing herself as well as her child. Sonja's despair and actions were narrated as follows:

"I felt like committing suicide… and I wanted to throw the child under a train… I just felt very sad to think that (subject sniffs) that it had to turn out this way… um when I was discharged from hospital that day um then I came home, then I called my mother and then I told her and then I wanted to take pills and then I walked down to the railway line. Then I wanted to throw myself under the train and then a young guy came, came and took me from the railway line." (Sonja)
"Ek het gevoel om selfmoord te pleeg… en ek wou die kind onder 'n trein gegooi het… Ek het net baie hartseer gevoel om te dink dat (subjek snuif) dat dit so moet gebeur het… um toe ek daai dag uit die hospitaal ontslaan word um toe kom ek huis toe, toe roep ek my ma en toe vertel ek vir haar en en toe wil ek pille gedrink het en toe stap ek af treinspoor toe. Toe wil ek my onder die trein gegooi het en toe kom 'n ander klong, kom haal hy my van die spoor af." (Sonja)

According to Stevens et al. (cited in Withell, 2000), an HIV-diagnosis is commonly characterised by distress and feelings of devastation that may progress to suicidal thoughts. Catz et al. (2002) stated that a person's HIV-positive diagnosis is often accompanied by depression, suicidal ideation and suicide attempts. It seems from the above narrations of the participants that the illness is constructed as a death sentence with no hope for a future life.

Elna also contemplated suicide after receiving the news that she was HIV-positive, but her concern and love for her young daughter gave her hope and made her change her mind:

"The first time I got the news I felt but I would rather be dead, but after that I said to myself, you have a child you have something to live for. And she's still very young she needs the attention of her parents so what's the use of committing suicide or doing something about the matter. I already have it and I have to accept it like that…" (Elna)
"Eerste keer toe ek die nuus kry het ek gevoel maar ek wil liewer dood wees, maar daarna het ek gesê vir myself, jy het 'n kind jy het iets om voor te lewe. En sy is nog baie jonk sy het die aandag nodig van haar

ouers so wat's die moeite werd om selfmoord te pleeg of iets te doen aan die saak. Ek het dit klaar en so moet ek dit aanvaar…" (Elna)

The researcher experienced Elna as a person with a very positive attitude to life. In the literature it is emphasised that dependent children can encourage a positive attitude to life and decrease depressive feelings (Andrews et al., cited in Withell, 2000). The effect of children on a positive diagnosis will be discussed further in the section on coping mechanisms in this chapter.

5.1.4 Anger and blame

Feelings of anger and blame were only expressed by participants that were certain about who had infected them with HIV. Some participants were uncertain and worried at the time of the diagnosis about who were responsible or to blame for the illness, themselves or their partners:

"I thought where does this come from. Who is now to blame, me or my husband or who. And it's too sudden, I mean…we don't like sleeping around, how could it have happened?" (Ann)

"Ek het gedink waarvandaan kom dit. Wie is nou te blame ek of my man of wie. En dit is te skielik, ek meen... ons is nie lief vir rond slaap nie, hoe kan dit gebeur het?" (Ann)

"Then I think oh dear why did S (her husband) do it or why did I do it. We don't know which one of us has now given the sickness to the other." (Rosy)

"Dan dink ek ai hoekom het S (haar man) dan nou dit gedoen of hoekom het ek nou dit gedoen. Ons weet nou nie wie of wie watter een het nou die siek nou vir mekaar gegee het." (Rosy)

"Now I don't know if I have also infected my boyfriend (subject cries) and he himself also doesn't know that I'm sick." (Mariana)

"Nou weet ek nie of ek my boyfriend ook aangesteek het nie (subjek huil) en hy homself weet ook nie dat ek siek is nie." (Mariana)

Most of the participants in the present study that were sure that they had been infected by their partners or previous partners, expressed feelings of anger and/or blame towards that person. Maggie narrated her anger towards her previous partner as follows:

"All I thought of was how could it be possible, why did I get it and I felt like going to throttle that blighter." (Maggie)

"Al wat ek aan gedink het hoe kon dit moontlik wees, hoekom het ek dit gekry en ek was lus om daai mannetjie te gaan wurg." (Maggie)

When Joeyce saw her previous partner, shortly after her diagnosis, she felt extremely angry towards him for infecting her with the virus:

"Then one day my boyfriend and I went to Pick 'n Pay, then I saw him (her previous boyfriend) in front of Pick 'n Pay with a guitar and a big poster he is HIV+. People were throwing money into the hat he had put down there. I looked at him, then I walked away then I said to my boyfriend it was him who had given it to me. I just felt like kicking the thing in his face, and on top of it people were throwing money into his hat. He is a murderer..." (Joeyce)

"Toe gaan ek en my kêrel eendag Pick 'n Pay toe, toe sien ek hier sit hy (haar vorige kêrel) voor Pick 'n Pay met 'n kitaar en 'n groot bord hy is HIV+. Mense gooi vir hom net so geld in in die hoed wat hy nou daar neergesit het. Ek het hom so gekyk, toe stap ek toe sê ek vir my kêrel dis hy wat dit vir my gegee het. Ek is toe sommer lus en skop die ding in sy gesig, dan gooi die mense nog geld in sy hoed. Hy is 'n moordenaar..." (Joeyce)

Sylvie narrated extremely negative feelings towards her husband for infecting her, as he was her only sexual partner:

"...but I felt a bit of hatred towards my husband. I I didn't...I wasn't happy because I felt he had affected me through that...Mostly I felt I um I am alone and so on, he does happen to be my husband and then I came there and I say he was the only man, there was nobody else in my life with whom I had a sexual relationship." (Sylvie)

"...maar ek was 'n bietjie haatlik teenoor my man. Ek ek het... ek het nie ek was nie tevrede nie, want ek het gevoel daardeur het hy vir my geraak... Meestal het ek gevoel ek um ek is alleen en so aan, hy is wel my man en dan het ek daar gekom en ek sê dit was die enigste man, daar was nie iemand anders in my lewe met wie ek 'n seksuele verhouding gehad het nie." (Sylvie)

Hester blamed her husband for infecting her and her child with HIV:

"Because the problem was when he (her husband) wanted to pretend that I gave it to him. And I blame him it's because of him that my child and I suffer from it ... And then I thought by myself...it was just him (her husband) who was the problem, because he worked on the long road. Now I was pregnant and constantly when he came home from the long road, he had to be at clinics for injections. Then I asked him why, but he said he doesn't sleep around." (Hester)

"Want die probleem was toe hy (haar man) wil voorgee ek het dit vir hom gegee. En ek blameer vir hom dis deur hy dat ek en my kind daar onder deur ly... En toe het ek by myself gedink... dan net hy (haar man) wat die probleem gewees het, want hy het op die lang pad gewerk. Nou ek was swanger en gedurig is hy van die lang pad af gekom het, dan moes hy by klinieke wees vir inspuitings. Dan vra ek vir hom hoekom, maar hy sê hy slaap nie in die rondte nie." (Hester)

In the literature it is stated that men are inclined to deny their responsibility for infecting their partners. According to Haram (2001) it is commonly acknowledged in most African countries that when men are infected, their wives are suspected of infidelity, but when women are infected they are assumed to have had multiple partners.

It is interesting to note that Nossie was the only participant not blaming her partner for infecting her; all she wanted was his support and love:

"I wasn't angry with him that it had happened (that her boyfriend had infected her), but I feel he must also talk to me. Also tell me he's sorry because this has now happened to us...I don't live with anger towards him because of it." (Nossie)

"Ek was nie kwaad vir hom dat dit gebeur het nie (oor mansvriend haar geïnfekteer het), maar ek voel hy moet met my ook gesels. Ook vir my sê ek is jammer omdat dit nou gebeur het met ons... Ek lewe nie kwaad vir hom deur middel van dit nie." (Nossie)

Two respondents (Maggie and Sonja) blamed themselves for getting infected and this led to feelings of self-disappointment:

"I was very disappointed in myself, because I know I had been negligent and I didn't want to listen. Each time I came to the clinic with the same problem. They gave me treatment for it, they warned me against it." (Maggie)

"Ek was baie teleurgesteld in myself, want ek weet ek was nalatig en ek wou nie luister nie. Elke keer kom ek met dieselfde probleem by die kliniek. Hulle gee vir my behandeling daarvoor, hulle waarsku my daarteen." (Maggie)

"To think that it's my fault that I have that sickness...I was almost, how can I say it, one can say I was a prostitute... (subject sniffs) then I made money... perhaps we had nothing and then perhaps I buy something ...I actually feel bad about it and um...now what else can I say it's my fault..." (Sonja)

"Om te dink dat dit is my skuld dat ek daai siekte het... Ek was amper hoe kan ek nou weer sê, sê maar 'n prostituut gewees... (subjek snuif) dan het ek nou geld gemaak nou... ons miskien niks het nie en koop ek miskien iets... Ek voel eintlik sleg daaroor en um... nou wat kan ek anderste dis my skuld..." (Sonja)

It is interesting to note that Elna was one of the few participants who did not experience feelings of blame at the time of diagnosis, she felt that she was just unfortunate to have been infected with the virus:

"I only said to myself why did it have to happen to me, but afterwards just thought but it could happen to anyone. It's through many things sex anything. That's how you get it, is not just because of badness or things like that." (Elna)

"Ek het ge net vir myself gesê hoekom moet dit met my gebeur, maar agterna maar net gedink maar dit kan met enigeen gebeur. Dit is deur baie dinge seks enigiets. Dit is hoe jy dit kry, is nie net van slegheid of dinge soos daai nie." (Elna)

The above citations show that feelings of anger and blame were not experienced by all the participants in the present study. Nevertheless, some participants blamed themselves for getting infected with HIV and others blamed their partners or previous partners. The experiences of these women seem to be informed by an understanding that HIV/AIDS is a deadly illness that one should be ashamed of and be blamed for.

5.1.5 Guilt

In the present study some of the participants experienced guilt as an emotion because of being responsible for infecting their partners. It is quite surprising that more of the participants articulated guilt feelings for infecting their partner than for infecting their child/children. These participants verbalised feelings of guilt towards their partners as follows:

"Yes, uh I uh, the time that P (her boyfriend) went with me, I felt quite guilty. I looked at it in this way, I had a guy before P. I wasn't aware that perhaps I had AIDS. But that day I felt I was the one who had the sickness on me and I have now had sex with P…I love P, his support is very good, but when I look at him I think that perhaps he is still thinking of the day we were at the doctor, when she gave us the results… I have asked if he thinks badly of me and if he, I'm the one who transmitted the germ to him and so." (Maggie)

"Ja, uh ek uh, die tyd toe P (haar mansvriend) saam gegaan het, het ek nogal baie skuldig gevoel. Ek het dit so gevat ek het 'n outjie voor P gehad. Ek was nie bewus dat ek miskien AIDS het nie. Maar daardie dag het ek gevoel ek is die een wat die siekte op my het en ek het nou saam met P seks gehad… Ek is lief vir P, sy ondersteuning is baie goed, maar as ek vir hom so kyk dan dink ek daaraan hy dink miskien nog altyd

daaraan die dag toe ons by die dokter was, wat sy vir ons die uitslae gegee het… Ek het al vir hom gevra of hy snaaks dink van my en of hy, ek is die een wat die kiem aan hom oorgedra het en so." (Maggie)

"Look, when I look at him then I just start crying (subject cries)…To think it's through me, I gave it to him…" (Joeyce)

"Kyk as ek so na hom kyk dan huil ek sommer (subjek huil)… Om te dink dit is deur my ek het dit vir hom gegee …" (Joeyce)

"And then I thought but I had gone out with a man… If he now is, he has not even had himself tested or so. And that bothered me a lot and I also felt guilty….about that." (Rosy)

"En toe dink ek mos nou ek het mos nou al met 'n man uitgegaan… As hy dan nou is, hy het hom nog eers nie getoets of so nie. En dit het my baie gepla oor die en ek het skuldig gevoel ook… daaroor." (Rosy)

Mariana's feelings of guilt for possibly infecting her boyfriend made her feel obliged to stay with him, especially for the reason that he might infect another woman with the virus. This possibility of infecting another person also made her feel very guilty:

"if he now has the sickness, sister, then I also can't leave him like that.. I'm scared he will get another girlfriend then he could also infect the girlfriend… Because I'm guilty of that, sister. Because I gave him the sickness." (Mariana)

"As hy nou die siek het, suster, dan kan ek hom ook nie so los nie… ek is bang hy gaan weer 'n ander meisie kry dan kan hy die meisie ook besmet… Omdat ek skuldig is daaraan suster. Omdat ek hom die siek gegee het." (Mariana)

Seven of the participants in the present study had one child who was HIV-positive and one participant, Ann, had two HIV-infected children. Only two of the eight participants with infected children, Sonja and Sylvie, revealed guilt feelings for infecting or possibly infecting their children:

"I feel, how can I say um (subject sighs)… um I now feel sad about things that have happened to me and now my child (her baby) is to think that he now also has that sickness…" (Sonja)

"Ek voel hoe kan ek sê um (subjek sug)… um ek voel nou hartseer oor dinge wat nou gebeur het teenoor nou oor my en nou is my kind (haar baba) om te dink dat hy ook nou daai siekte het…" (Sonja)

"And then I started wondering what about my children…and what am I going to do if I have to know any of them had contracted the illness?" (Sylvie)

"Toe het ek begin te wonder wat van my kinders… en wat gaan ek doen as ek moet weet van hulle het die siekte opgedoen?" (Sylvie)

Hackl et al. (1997) stated that HIV-infected mothers may experience overwhelming guilt as a result of their belief that their behaviours have brought harm directly (in vitro infection) or indirectly (leaving orphans through death) to their children. In the light of this, it is surprising then that the majority of the participants in the present study did not reveal guilt feelings for infecting their children. They did, however, verbalise guilt feelings for not being able to care for their children in the future should they fall ill or die. Their experiences of guilt for the possibility of abandoning their children through death seemed to be informed by a belief that they would then fail as primary caregivers and mothers.

5.1.6 Concerns about children

At the time of receiving the news of a positive diagnosis, many women in the present study stated immediate concerns regarding their children's well-being and future. For Maggie, Joeyce and Sylvie an HIV-diagnosis meant that they would be separated from their children through death much sooner than they had expected. They narrated their concerns as follows:

"But as I walked home then I thought of my child, I have an illness that can't be cured, what is my child going to do, where is he going to live, how long will I still be with him?" (Maggie)

"Maar soos ek gestap het huis toe het ek gedink aan my kind, ek het 'n siekte wat nie kan genees raak nie, wat gaan my kind maak, waar gaan hy bly, hoe lank gaan ek by hom wees?" (Maggie)

"That time I just thought of my child, how long how long still, how long I'm going I'm going to live. To think I have a small child that I still have to see grow up." (respondent cries) (Joeyce)

"Daai tyd het ek net gedink om my kind, hoe lank hoe lank nog, hoe lank gaan ek nog gaan ek nog lewe. Om te dink ek het 'n klein kind wat ek nog moet sien groot raak." (respondent huil) (Joeyce)

"And my thoughts just dwelt on my children dwelt on my children, how must I tell them what must I tell them what must I do. And how long like... oh well, I live from day to day anyway, how long am I still going to live..." (Sylvie)

"En my gedagtes het geloop op my kinders het geloop op my kinders, hoe moet ek vir hulle sê wat moet ek vir hulle sê wat moet ek doen. En hoe lank soos... ag ek lewe tog maar van dag tot dag, hoe lank gaan ek nog lewe..." (Sylvie)

From the start of the interview and throughout, Sonja narrated feelings of extreme sadness and loss because of her baby being HIV-positive and having been taken away from her by Welfare. Consequently, she experienced a double trauma and loss at the time of her diagnosis. She narrated the painful emotions accompanying her positive diagnosis and the loss of her baby and motherhood as follows:

"I feel how can I say um (subject sighs)… um I now feel sad about things that have happened to me and now my child (her baby) is to think that he now also has that sickness… I want him to come back (subject cries)…Just my baby he must come home…" (baby was placed in Nazareth House by Welfare) (Sonja)

"Ek voel hoe kan ek sê um (subjek sug)… um ek voel nou hartseer oor dinge wat nou gebeur het teenoor nou oor my en nou is my kind (haar baba) om te dink dat hy ook nou daai siekte het… Ek wil hê hy moet terug kom (subjek huil)… Net my baby hy moet huis toe kom…" (baba deur Welsyn in Nazareth Huis geplaas) (Sonja)

Nossie's baby girl was the most symptomatic of all the HIV-infected children in the present study. She verbalised her concern for her very ill child as follows:

"…then I said if I now have to die then my child must go with me. Because when my child suffered so when she was lying there… and then the doctor came to me, then she told me I mustn't worry, we're going to save your child's life. There are um um um many problems, but they are trying their best for her." (Nossie)

"…toe sê ek as ek nou moet dood gaan dan moet my kind saam met my gaan. Want toe my kind so gely het toe sy daar lê… en toe die dokter na my toe kom, toe sê sy vir my ek moet nie bekommerd wees nie, ons gaan jou kind se lewe red. Daar is um um um baie probleme, maar hulle probeer hulle bes vir haar." (Nossie)

It was clear throughout the interviews that all the participants had immediate concerns regarding their children when they heard that they were HIV-infected. They were worried about their children's well-being and future, should they as mothers and primary caregivers fall ill or die. These initial concerns became everyday concerns for the participants, thus adding to the daily psychological distress and consequences of living with HIV/AIDS. Concerns regarding children are discussed in more detail in following sections of this chapter that deal with stigmatisation and fear of disclosure, management of illness symptoms, psychosocial losses, and anxiety regarding duration of life, survival and future.

5.1.7 Concerns regarding disclosure

Some of the participants were immediately concerned and anxious at the time of the diagnosis about disclosing their HIV-status to close family members, because they feared being rejected and shunned. Elna expressed her concern and anxiety regarding the consequences of disclosing her status as follows:

"But what am I going to do when I get home and as I walked from the clinic I was thinking, how am I how am I going to tell this to my parents, how am I going to tell this to my boyfriend, how will they accept it? What am I going to do if they turn me away… if they want nothing to do with me and things like that." (Elna)

"Maar wat gaan ek doen as ek by die huis kom en toe soos ek van die kliniek af loop het ek nog geloop en dink, hoe gaan hoe gaan ek dit vir my ouers vertel, hoe gaan ek dit vir my boyfriend vertel, hoe gaan hulle dit aanvaar? Wat staan my te doen as hulle my gaan weg wys… hulle wil nie met my te doen hê nie en dinge soos daai." (Elna)

Already at the time of receiving the news that they were HIV-positive Mariana and Bertha made definite decisions not to disclose their illness to their mothers. Mariana felt very sad about not being able to tell her mother or family:

"I felt very sad… and I didn't tell my parents. To this day they don't know that I'm ill…" (respondent cries) (Mariana)

"Ek het baie hartseer gevoel… en ek het nie vir my ma-hulle gesê nie. Tot vandag toe weet hulle nie dat ek siek is nie…" (respondent huil) (Mariana)

Bertha narrated that she could not confide in her mother, because she could not trust her to keep her diagnosis a secret:

"And then I didn't tell my mother, next day the people will say I have I have those things. That will be poison…" (Bertha)

"En toe het ek mos nie vir my ma vertel het nie, oormôre dan sê die mense ek het ek het daai goeters. Dit gat mos gif wees…" (Bertha)

It is clear that already at the time of diagnosis these participants were extremely apprehensive about the consequences of disclosing their HIV-positive status, particularly because they feared harsh judgement and rejection from close family members. These

reactions show the immediate and devastating effect that HIV/AIDS as a highly stigmatised illness had on these women. Their fear of disclosure seems to be informed by an understanding that in their community a person with HIV/AIDS will be stigmatised, shunned and victimised. Concerns and fears regarding disclosure were verbalised by all the participants in the present study and will be discussed in more detail in section 5.2.2 of this chapter.

5.1.8 Summary

The initial reactions of the participants in the present study to a positive HIV-diagnosis show that it was an extremely difficult and challenging experience for all of them. The illness experience was constructed as traumatic; a powerful psychological shock that caused the women immediate emotional distress. The instantaneous reactions of almost all the participants when they heard that they were HIV-infected were speechlessness, motionlessness and numbness. One participant nearly fainted and described her body as becoming weak when she heard that she was HIV-positive. The participants experienced feelings such as shock, disbelief, sadness, hopelessness, despair, disappointment, blame, and guilt, as well as concerns regarding children and concerns regarding disclosure. The majority of the participants cried and experienced intense grief when they heard that they were HIV-positive. According to many writers, depressive feelings, sadness, hopelessness and despair are often the first responses that are likely to occur after an HIV-diagnosis, which can develop into a more serious depressive condition as the illness progresses (Hudson et al., 2003; Kaplan et al., 1997; Murphy et al., 2002).

According to Heath and Rodway (1999), some writers described certain feelings as being more prevalent at different times in the disease process, such as shock at the time of diagnosis and feelings regarding spiritual/existential issues at a later phase. Other writers stated that some women face spiritual/existential issues immediately after diagnosis because of the connection between AIDS and premature death (Christ et al., cited in Heath & Rodway, 1999). In the present study the participants experienced both feelings

associated with immediate trauma and feelings regarding issues of life and death at the time of diagnosis. All the participants narrated having thoughts of death and dying, because of the illness being incurable. The majority of the participants had suicidal thoughts and one participant actually attempted suicide, which shows the intense psychological effect the diagnosis had on them. Therefore, it can be said that the participants in the present study experienced their HIV/AIDS diagnosis as a severely life-altering event, a devastating and irreversible condition, and ultimately a death sentence.

The participants also verbalised thoughts about who was to blame for the illness, them or their sex partners. The experiences of these women seem to be informed by an understanding that HIV/AIDS is not simply a deadly illness or "the progressive exposure of fragile vital organs to the ravages of common infections" (Clatts et al., cited in Lupton, 1995, p.57). Rather, there seems to be a notion that the person infected with HIV/AIDS is a certain kind of person, "socially and morally defined" – a person that is blameworthy (Clatts et al., cited in Lupton, 1995, p.57). To the extent then that a discourse of HIV/AIDS can be discerned, it seems that within this discourse there also is the assumption that HIV/AIDS is punishment for living unhealthy or immoral lives (Gwyn, 2002).

At the time of diagnosis all the participants thought about the consequences and reactions of others should they decide to disclose their HIV-status. Most of the participants contemplated selective disclosure and some decided not to disclose their HIV-status at all. Directly after the diagnosis almost all the participants isolated themselves from others and preferred not to socialise with friends and/or family. According to these women, when they heard that they were infected with this stigmatised and deadly virus their lives chanced instantaneously. These feelings and reactions again seem to be based on an assumption that HIV/AIDS is an incurable and deadly illness. In other words, it can be argued that there was a larger discourse of HIV/AIDS impacting on their illness experience, with one of the central tenets of the discourse being that HIV/AIDS is a fatal illness.

Furthermore, the participants verbalised that they had disturbing thoughts about the loss of life and relationships, and concerns about their child/ren's well-being and future should

they as mothers and caregivers fall ill or die. It seems that these thoughts on the probability of abandoning their children and thus failing as mothers are informed by two possible discourses: one concerning HIV/AIDS as an illness that is deadly and shameful, and one concerning what it means to be a good mother.

In the participants' accounts of their process of finding out about their diagnosis, the first discourse that can be traced is a discourse of HIV/AIDS within which it is assumed that HIV/AIDS is an incurable and deadly illness, and that it is a shameful illness for which someone should be blamed. Also discernable, however, is a discourse of mothering, what it means to be a good mother. That this mothering discourse is also operative here is suggested by the prominence of the participants' concerns regarding their caregiving roles. In this highly gendered discourse it seems to be assumed that women's most central role is that of taking care of their children. It will be argued in further sections that this was an important discourse that impacted on the illness experience of the participants in very significant ways. Both these larger discourses also seem to be apparent in the participants' descriptions of living with HIV/AIDS, and will be highlighted in further sections.

All the above narrations are the retrospective views of the participants of their experiences at the time of diagnosis. It would have been interesting to have interviewed these women at the time of their diagnosis, because it is not known to what extent their later illness experiences shaped their memories of their diagnosis.

Because of disclosure being such a serious concern for the participants from the time of diagnosis, the next section will focus on the stigma attached to the illness and the fear of disclosing their illness condition to others. It will be showed how this fear of disclosure impacted on their lives and daily functioning.

5.2. Stigmatisation and fear of disclosure

5.2.1 Stigma and HIV/AIDS

All of the participants in the present study were very much aware of the stigmatisation attached to HIV/AIDS and the harmful consequences thereof. The participants' construction of HIV/AIDS was that of a shameful and life-threatening illness with no known cure. As has been mentioned before in Chapter 1, state health facilities/services did not provide anti-retroviral treatment (ART) for patients until recently. These women did not have the financial means for private health consultations or treatment and were obliged to make use of state-provided health services. Consequently, most of the participants in the present study were not even aware of or informed about medication or treatment that could prolong their lives. Thus, for them the illness meant an early death if no cure was found.

According to the participants in the present study, people fear getting infected with the virus through contact with HIV-positive persons like themselves. Their narrations prove that not only is the illness stigmatised but also the infected person branded as disgraceful:

"Because to the people it's, it's a terrible illness to other people. It was also like that for me before I knew. I mean one sees things on the TV and on the news… that about the illness and people who have died of the illness and there are no cures and such things." (Ann)

"Want dit is vir mense, dit is 'n verskriklike siekte vir ander. Vir my was dit ook so voor ek nie geweet het nie. Ek meen mens sien mos dinge op die TV en op die nuus… daai oor die siekte en mense gesterwe van die siekte en daar is nie geneesmiddels en daai goed nie." (Ann)

"Look, today it just is like that, people don't want to eat with you out of the same thing, they don't want to drink with you, they don't want to talk to you, they don't want to touch you, because you have AIDS." (Maggie)

"Kyk vandag is dit mos maar so, mense wil nie saam met jou eet uit een ding uit nie, hulle wil nie saam met jou drink nie, hulle wil nie saam met jou gesels nie, hulle wil nie aan jou vat nie, want jy het AIDS." (Maggie)

"I don't know if they're scared of the people with HIV or what, but they don't want to be near the people with HIV… Then I feel very bad again and then I think oh, I have HIV myself…" (Rosy)

"Ek weet nie of hulle bang is vir die mense met HIV of wat nie, maar hulle wil nie naby die mense is met HIV nie… Dan voel ek weer baie sleg en dan dink ek ai, ek het self HIV…" (Rosy)

A work colleague of Maggie was harshly judged, avoided and rejected after his HIV-status had became known to the people at their workplace:

"And they took long before they first heard he had AIDS and they, he explained to them. So many closed their doors in his face. And washed their cups and things in jik (bleach), everything, he can't sit down then they vacuum or they wash the couches, so." (Maggie)

"En hulle het lank gevat voordat hulle eers gehoor het hy het AIDS en hulle, hy het vir hulle explain. So baie het hulle deure in sy gesig toegemaak. En hulle koppies en hulle goed in jik gewas, alles, hy mag nie sit nie dan stofsuiwe hulle nou of hulle was die banke, so." (Maggie)

Bertha, Sonja and Nossie were the only three participants who mentioned the stigmatisation attached to HIV/AIDS because of the virus being sexually transmitted and the perception that the illness is caused by immoral behaviour. These narrations also show their feelings of shame, guilt and self-blame for getting infected with the virus. They respectively said:

"I told nobody, nobody, because I just feel ashamed with my face… just shame. But it's not nice, because I didn't know it, really, I never knew it… I don't want to tell anybody, because it's a disgrace…" (Bertha)

"Ek het vir niemand vertel nie, vir niemand nie, want ek voel net skaam met my gesig… net skaamte. Maar dit is nie lekker nie, want ek het dit nie geweet nie, regtig nie, ek het dit nooit geweet nie… Ek wil vir niemand vertel nie, want dit is 'n skande…" (Bertha)

"I felt very hurt… they will take it as um it's your own fault, because you slept around and… then you got that illness…" (Sonja)

"Ek het baie seer gevoel… hulle sal dit so vat um dis jou eie skuld, want jy het rond gegaan en… toe kry jy nou daai siekte…" (Sonja)

"But it's going to it's going to hurt me. Perhaps the people say, are you going around with that woman she's HIV she has AIDS, man. You know, like that. The "vuilsiek" is what people call it." ["vuilsiek" literally means "dirty illness", but "vuilsiekte" is also a medical term for syphilis and could be used informally for any venereal infection] (Nossie)

"Maar dit gaan my nog dit gaan my nog seer maak. Dalk sê mense miskien nou, loop jy met daai vrou sy is HIV sy het AIDS man. Jy weet so. Die vuilsiek die mense noem hulle mos dit." (Nossie)

From the above accounts it seems apparent again that the illness is constructed as something to be extremely ashamed about; something that is morally wrong, "filthy" and "bad". Gaskins (1999) noted that the general public continues to recognise the disease as being the result of behaviours and stigmatised lifestyles that are not overlooked by society. Zlotnik stated that "...persons affected by AIDS are multiply stigmatised because AIDS often is perceived by society as shameful, mysterious, contagious and sexually transmitted" (1987, p. 2). According to Gaskins (1999), women dread the moral judgment that "they get what they deserve to get". Sherr (1995) pointed out that the blaming of people with HIV/AIDS for their condition has been extensively reported. In the study conducted by McGinn (1996), all the participants voiced displeasure about irrational fears of contagion and negative attitudes regarding perceived immoral behaviour they encountered from members of their community. In the present study the participants' construction of HIV/AIDS as shameful and blameworthy seems to be shaped by their traditional and cultural beliefs about sex and sexuality. Lesch (2000) found that young Coloured women's constructions of sex as wrong and dangerous were influenced by their mothers belief's and traditions.

In the present study many participants narrated strong feelings of shame regarding their illness. Bertha felt embarrassed and regretful about being HIV-infected:

"I didn't tell anybody, nobody, because it's a disgrace... I just feel ashamed with my face... just shame. But it's not nice, because I didn't know it... It seems difficult to me (to disclose status), I'm very ashamed of it ashamed..." (Bertha)

"Ek het vir niemand vertel nie vir niemand nie, want dit is 'n skande... ek voel net skaam met my gesig... net skaamte. Maar dit is nie lekker nie, want ek het dit nie geweet nie... Dit lyk vir my moeilik (om status bekend te maak), ek is baie skaam daaroor skaam..." (Bertha)

In the literature it is clear that feelings of shame and embarrassment are common for women infected with HIV (Schrimshaw, 2003). Although some men may experience this, it seems that women have introjected social views and feel more ashamed of their status (Broun, 1999). Broun (1999) stated that regardless of how women got infected, many feel a great deal of shame, guilt and loneliness. These suggestions that women feel more

ashamed than men when they are HIV-infected, indicates the discourse of HIV/AIDS as a shameful illness that may be gendered.

Rosy and Sylvie felt as if feelings of shame would accompany them till their deathbed:

"I thought uh the day that I perhaps die, look, one has a postmortem about the death and then later they would have known why, because I would be dead... Perhaps I am bed-ridden before I die, have to lie in bed perhaps and and sick and suffer I mean. I suffer from sickness and now I'm thinking oh heavens, wat will the people say now or what won't they know now..." (Rosy)

"Ek het gedink uh die dag as ek nou miskien doodgaan, kyk 'n mens kry mos 'n lykskou oor die dood en dan sal hulle mos later van tyd geweet het waaroor, ek het mos nou gesterwe... Ek lê miskien nou voor ek nou dood, gaan lê ek nou miskien en en siek en ly nou bedoel ek nou. Ek ly siek en nou dink ek ai jinne wat sal die mense nou sê of wat nou nie weet nie..." (Rosy)

"They would just have to hear and um I wouldn't like them to see me suffer or...I'll probably never talk to a social worker or someone down there...Perhaps I land there in a hospital when I get sick and of uh and there it gets blurted out this is what my illness is and so." (Sylvie)

"Hulle moet maar net hoor en um ek wil nie graag hê hulle moet my sien ly of... ek sal seker nooit met 'n maatskaplike werkster of iemand daar onder praat nie... Ek beland miskien daar in 'n hospitaal dat ek siek word en van uh en daar lap dit uit dit is wat my siekte is en so." (Sylvie)

According to Walker et al. (1996), stigma is attached to the social or cultural groups into which many people with HIV/AIDS fall, the physical disfigurement associated with AIDS, the cognitive decline of people with AIDS, the lack of a known cure, the often unrealistic fear of contagion, and many people's perception of immorality associated with the illness. For the participants in the present study, stigma was associated with the fatality of the illness, suffering and death, other people's fear of contagion as well as the general perception that AIDS is spread through immoral behaviour. Given then that HIV/AIDS is so clearly associated with immoratily, suffering and death, it seems that people with HIV/AIDS in their community are seen as disgraceful and as "outcasts".

Moneyham et al. (cited in Gaskins, 1999) explored HIV-related stigma in a focus group of HIV-infected women. According to her, the women's perceptions of stigma came from what they described as distancing, overgeneralising stereotypes, social discomfort and pity. Distancing was described as their perception of the behaviour of others to avoid close

contact with HIV-infected people. Overgeneralising stereotypes related to other people's predisposition to associate HIV-infected individuals with stigmatised life-styles like sexual promiscuity and drug use. People's reluctance to address their illness was seen as social discomfort.

In the present study only Elna narrated that people felt sorry for her because of being HIV-infected. She disliked the idea of being pitied and expressed the need to be accepted and treated like all other people:

"It bothers me yes, I I I don't want to be looked at with such attention, because I accept that I have it but I don't think about it... I want others also to treat me as any other person is treated. I don't want them to look at me with that attention or to pity me or so." (Elna)

"Dit pla vir my ja, ek ek ek wil nie met so aandag aangekyk, omdat ek aanvaar ek het dit, maar ek dink nie daaraan nie... verlang ek ander moet ook vir my behandel soos enige ander mens behandel word. Ek wil nie hê hulle moet vir my kyk met daai aandag of my jammer kry of so nie." (Elna)

In the study conducted by Moneyham et al. (cited in Gaskins, 1999), they also found that women felt that other people pitied them because of AIDS generally being perceived as a terminal and fatal illness. This again suggests a discourse of HIV/AIDS being an incurable and deadly illness.

5.2.2 Disclosure and fear of rejection and losses

All the participants in the present study reported fear of disclosing their HIV-status to family members and friends because of possible rejection and the loss of relationships and friendships. Essentially, the participants feared that important others would reject them by withdrawing their love, acceptance and attention, which the participants were used to:

"I think they'll leave me as a friend, because life is like that nowadays... everybody rejects you if they hear that you have the sickness." (Elna)

"Ek dink hulle sal my verlaat as 'n vriend, want die lewe is maar deesdae so... almal verwerp jou as hulle hoor jy het die siek." (Elna)

"We don't want the whole world to know... you understand? Not even family, otherwise we'll no longer have any friends... Just scared that it will um become known, that everybody will know we have HIV." (Ann)
"Ons wil nie hê die hele wêreld moet weet nie... verstaan u? Nie eers familie nie, anders sal ons vrinde nie meer het nie... Net bang lat dit dit um kom uit, dat almal gaan weet ons het HIV." (Ann)

"They (the community) will be scared to talk to me... or to drink or to eat with me..." (Mariana)
"Hulle (die gemeenskap) sal bang wees om met my te praat... of saam met my te drink of te eet..." (Mariana)

"The community around, no one knows, because I'm too scared people will reject me if I had to tell them. People always come to me and so on, then I make them tea. If I had to tell them they won't come to me any longer. That's what I feel... I'm scared that people who don't yet know that I'm HIV AIDS HIV+ and that people uh uh uh will live very differently with me." (Nossie)
"Die gemeenskap rondom niemand weet nie, want ek is te bang mense gaan my verstoot as ek nou vir hulle gaan sê. Mense sal altyd na my toe kom en so aan, dan maak ek vir hulle tee. As ek vir hulle gaan sê dan gaan hulle nie meer by my kom nie. Dis wat ek voel... Ek is bang dat mense wat nog nie weet ek is HIV AIDS HIV+ nie en dat mense uh uh uh baie anders met my sal lewe." (Nossie)

In her study of fatal or chronic illness, Charmaz (1997), found that most women wanted to be known for attributes other than serious illness. Therefore, they would hide their illness or avoid disclosures when they saw that illness could cloud other people's images and judgements of them.

Many of the participants in the present study felt that people would be afraid to touch them, even be anxious to come close to them physically. Certain participants also anticipated that people would be fearful to enter their houses or to use their crockery, because of their naive knowledge about the vection of the illness. This shows that the participants inherently feared the loss of normal day-to-day encounters, which can be considered basic dimensions of meaningful human relationships. Hester, Maggie and Nossie described their fear of these losses should they disclose their HIV-status:

",,, then I will hear it (that she is HIV+) every day and they (people in her community) will also not be the same towards me, Elsa... But then I think to myself, it's as if something is keeping me from telling, Elsa. I mustn't do it, because it will be the biggest mistake of my life... they wouldn't want their children to play with my children. They'll also not want to come to my house, to drink a cup of tea or coffee with me as usual. They'll be scared to talk to me or so... I don't feel like telling them." (Hester)

"...dan gaan ek dit (dat sy HIV+ is) elke dag hoor en hulle (mense in haar gemeenskap) sal ook nie meer met my dieselfde wees nie Elsa... Maar dan dink ek by myself, dis soos iets wat my weerhou Elsa. Ek moet dit nie doen nie, want dan is dit die grootste fout wat ek in my lewe gaan doen... hulle sal nou weer hulle kinders moet met my kinders speel nie. Hulle sal ook nie by my huis wil kom nie, soos gewoonlik met my 'n koppie tee of koffie te drink nie. Hulle sal bang wees om met my te praat of so... Ek voel nie om vir hulle te sê nie." (Hester)

"I don't really want them (her family) to find out what's the matter with me. It's a secret between me and P (her boyfriend) and God myself. Do you understand? Look, today it just is like that, people don't want to eat with you out of the same thing, they don't want to drink with you, they don't want to talk to you, they don't want to touch you, because you have AIDS." (Maggie)

"Ek wil nie eintlik hê hulle (haar familie) moet uitvinne wat makeer ek nie. Dit is 'n geheim tussen my en P (haar mansvriend) en God myself. Verstaan jy? Kyk vandag is dit mos maar so, mense wil nie saam met jou eet uit een ding uit nie, hulle wil nie saam met jou drink nie, hulle wil nie saam met jou gesels nie, hulle wil nie aan jou vat nie, want jy het AIDS." (Maggie)

"Then I felt that if I now tell the people, the people will never communicate with me or nobody will be interested in me...They're not going to want to talk to me and they'll ignore me. They're not going to want to even turn or swing to my side. If they see me, perhaps they'll look away or so... Because they they are like that towards the other other people. They snub people with TB straight off and so, I mean how are they going to treat me?" (Nossie)

"Toe voel ek nou as ek nou vir die mense gaan vertel gaan die mense nooit met my kan kommunikeer nie of niemand gaan in my belangstel nie... Hulle sal nie met my wil praat nie en vir my ignoreer. Hulle sal nie eers na my kant toe wil draai of swaai nie. As hulle my sien sal hulle miskien nou soontoe kyk of so... Want hulle hulle is met die ander ander mense is hulle so. Mense wat TB het jak hulle dan sommer so af en so, ek bedoel hoe gaan hulle met my maak?" (Nossie)

As a consequence of the stigma associated with HIV/AIDS, secrecy and concealment become of critical importance to women with HIV/AIDS (Siegel et al., cited in Hough et al., 2003). According to Hackl et al. (1997) and Hough, Brumitt, Templin, Saltz and Mood (2003), various studies found that women were concerned about disclosing their status because they feared the loss of relationships, therefore many mothers choose not to disclose the nature of their illness to their families, including their children and friends. Simoni and Ng (cited in Richardson et al., 2001) reported that nearly half of the women in their study disclosed to no one or to only one person. Gaskins (1999) stated that the

longer a person knows about his of her HIV-positive status or the further the disease progresses, the more likely he or she is to disclose. Sowell et al. (cited in Gaskins, 1999) found asymptomatic women to be the most reluctant to disclose their status.

Certain participants in the present study were cautious about disclosing their status to their mothers because they feared abandonment and rejection. The researcher found that those participants who could not share their positive status and illness condition with their mothers inherently wanted and needed their mother's understanding and support. These participants already felt hurt, abandoned and rejected by their mothers for not being able to share their deepest secret and concerns with them. Maggie feared immediate abandonment from her mother:

"If I had to tell her yes mom I have AIDS, she'll immediately say but my child take your things and go... Because we can't live with you... but that is how she's going to treat me. Then then it will cost me and P (her boyfriend) taking our things and leaving." (Maggie)

"As ek vir haar sê, ja ma ek het AIDS, dan gaan sy vir my onmiddellik sê maar my kind vat maar jou goedjies en gaan maar. Want ons kan nie saam met jou saam lewe nie... maar dit is soos sy my gaan hanteer. Dan dan kos dit my en vir P (haar mansvriend) om ons goed te vat en te loop." (Maggie)

Issiaka, Cartoux, Ky-Zerbo, Tiendrebeogo, Meda, Dabis and Van de Perre (2001) also found that fear of being rejected or abandoned was the main reason for their women participants not sharing their positive status with their partner or close family members, like their mothers.

Maggie narrated her fear of losing her child, should she inform her mother of her illness. Because of this possible loss she decided that she would only disclose her illness to her mother on her deathbed:

"Then she will also keep my child away from me. The day when I'm going to be saying farewell, then I'll tell her." (Maggie)

"Dan gaan sy my kind ook weg hou van my. Die dag wanneer ek afskeid gaan neem, dan sal ek dit maar vir haar sê." (Maggie)

Goicoechea-Balbona, Barnaby, Ellis and Foxworth (2000) stated that women fear disclosure because of the possibility of losing custody of their children.

Some participants feared the break-up of the relationship with their partners, should they disclose their HIV-status:

"…but he (her boyfriend) probably won't tell me if he has the sickness. If he tells me then I'll tell him that it's through me… If I say that then the two of us will split up…" (Mariana)

"… maar hy (haar mansvriend) sal seker nie vir my sê as hy die siek het nie. As hy vir my sê dan sal ek vir hom sê dis deur my… As ek vir hom nou sê dan gaan ons twee uitmekaar uit dan…." (Mariana)

The above findings correlate well with a study done by Grinstead et al. (2001), who reported that disclosure of a positive status was associated with the break-up of a marriage or relationship and being neglected or disowned by family.

Certain participants verbalised the possibility of many other losses, outside of their relationships with close family members and friends, should their illness be revealed. Nossie narrated that she would be forced to leave her neighbourhood and consequently lose her home and the community she knows well:

"I'll feel very very bad (if her status had to become known). I will really feel very terribly bad, because uh uh at this present moment things are still going well with the community around me, well with talking to each other and so on. But if they find out about it then it then it will drive me to many things… For example, I would rather have to move away to another place. There where people don't know of course. But it's still going to hurt me." (Nossie)

"Ek sal baie baie sleg voel (indien haar status bekend word). Ek sal rêrig baie verskriklik sleg voel, want uh uh op hierdie huidige oomblik gaan dit nog goed met die gemeenskap rondom, goed met mekaar gesels en so aan. Maar as hulle dit sal uitvinne dan gaan dan gaan dit vir my dryf na baie dinge toe… Soos byvoorbeeld ek sal maar nou uh iewers moet gaan wegtrek na 'n ander plek toe. Daar waar mense natuurlik nie weet nie. Maar dit gaan my nog seer maak." (Nossie)

Rosy mentioned that her illness hindered her chances of finding work, because people would not be willing to employ her should they be aware of her HIV-status:

"And then I think if I had to go and look for work, won't they perhaps draw blood from me again and then they will find out, no, but the woman has HIV, we can't take her on and so on." (Rosy)

"En dan dink ek as ek nou moet vir my gaan werk soek, sal hulle nie miskien bloed van my weer trek nie en dan sal hulle nou uitvinne, nee maar die vrou het nou HIV ons kan haar nie aanvat nie en so aan nie" (Rosy)

Not only do HIV-infected women fear that disclosure can diminish their chances of finding work and being employed, they also fear the detrimental effects of disclosure within the workplace. In the present study Maggie dreaded the idea of her HIV-status being disclosed to her work colleagues. She feared the same discrimination and rejection that a work colleague had experienced when his HIV-positive status became known to the people at their work:

"You know, I looked at that guy, they talked about him as if he were a piece of rotten cloth. Like that they humiliated him down to the ground and I didn't like it, because I knew it could perhaps happen in my case as well." (Maggie)

"Weet jy ek het daai mannetjie so gekyk, hulle het so gepraat van hom asof hy 'n stuk vrot lap is. So hulle het hom verneder tot op die grond en ek het nie daarvan gehou nie, want ek het geweet dit kan miskien met my geval ook gebeur." (Maggie)

Moneyham et al. (cited in Gaskins, 1991) found in a focus group of 19 women that their concerns about disclosure related to discrimination, confidentiality, and the context of disclosure. Discrimination was feared, especially from people with power over some aspect of the women's lives, such as their supervisors at work. As in the present study, these participants were concerned that people within their work environment could not be trusted with keeping their HIV-diagnosis confidential and should their status become known, they feared further discrimination.

Many participants in the present study decided not to disclose their HIV-status because they feared being verbally abused (victimised) by close family as well as people in general. They dreaded the idea of being scolded, insulted, sworn at or called names by others:

"No, I didn't tell them (her family)..., no, those ones are messy when they use abusive language... They come from there, then they drink over there. Then they come up then they disturb the people there. That's how their story works, no, they hurl abuse." (Bertha)

"Nee, ek het nie vir hulle (haar familie) vertel nie... nee daai eens is morsig as hulle skel... Hulle kom daarvandaan af, dan drink hulle daar ander kant. Dan kom hulle op dan hinder hulle die mense daar. So werk hulle storie, nee hulle skel." (Bertha)

"Then they (people in community) are going to call me bad names... or just look at me so nastily if I walk past them..." (Sonja)

"Dan gaan hulle (mense in gemeenskap) my lelik uitskel... of as ek verby hulle stap net so lelik aankyk..." (Sonja)

"I was too scared to talk to anybody... I think in a place like um this one where I now actually am, there'll be many insulting words thrown at you. There won't really be somebody who will um support you and so on..." (Sylvie)

"Ek was te bang om met iemand te praat... Ek dink in 'n plek soos um die waar ek nou regtig is, sal daar baie beledigende woorde geslinger word na jou toe. Daar sal nie regtig eintlik iemand wees wat sal um jou bystaan nie en so aan..." (Sylvie)

"I say I didn't tell my mother and also not the man (her boyfriend), next day he'll be telling me those things then he'll scold me..." (Bertha)

"Ek sê ek het nie vir my ma vertel nie en vir die man (haar mansvriend) ook nie, oormôre dan vertel hy vir my daai goed dan skel hy vir my uit..." (Bertha)

Maggie felt that she could not trust people with her diagnosis, because of the fear that they would say bad and hurtful things about her as a person:

"... they'll be scared. They are going to say no leave that woman, that woman is diseased. That's why I don't want to tell everybody. I don't feel ashamed about it, but I'm scared they're going to besmirch my name. They'll throw my name around ... but you also can't trust everybody..." (Maggie)

"...hulle gaan bang wees. Hulle gaan sê nee los daai vrou, daai vrou is sieklik. Daarom ek wil nie vir almal dit vertel nie. Ek voel nie skaam daaroor nie, maar ek is bang hulle gaan my naam besmadder. Hulle gaan my naam rond gooi... maar jy kan ook nie almal vertrou nie..." (Maggie)

Martinez et al. (2002) stated that after diagnosis women not only have to deal with the fear of having a contagious and progressively debilitating illness, but many also endure rejection and ostracism by family and friends and by society in general. In addition, Martinez et al. (2002) pointed out that many women with HIV/AIDS may experience physical harm from a person close to them as a direct result of their HIV-positive status.

Fear of physical abuse (victimisation) was described by certain participants in the present study:

"This worries me the most because I don't know how long he (her boyfriend) still has left to live, because the way he is thin at present, I can't take it when I look at it. What am I going to tell the people he died from.

They'll hurt me, they'll kill me... I'm just scared they could do something nasty...I had such a bad dream about it the other night...I dreamt how he (boyfriend's friend) assaulted me with a baton..." (Joeyce)
"Dit bekommer my die meeste want ek weet nie hoe lank het hy (haar mansvriend) nog oor om nog te lewe nie, want die way hy nou kan maer is, ek kan dit nie vat nie as ek dit nou so kyk nie. Wat gaan ek vir die mense sê waaraan hy dood is. Hulle gaan vir my seer maak, hulle gaan vir my dood maak... Ek is net bang hulle kan iets leliks aanvang... Ek het nou die aand so slegte droom gehad van dit... Ek het gedroom hoe rand hy (mansvriend se vriend) vir my aan met 'n battin..." (Joeyce)

"...but he'll probably not tell me if he has the sickness. If he tells me then I'll tell him...it's through me... Perhaps he'll hit me, hurt me..." (Mariana)
"...maar hy sal seker nie vir my sê as hy die siek het nie... As hy vir my sê dan sal ek vir hom sê... dis deur my... Miskien slat hy my, maak my seer..." (Mariana)

According to De Marco and Johnsen (2003), violence has been found to occur frequently among women with HIV/AIDS, and the illness itself is perceived to be an important factor in this victimisation. In a study of HIV-infected adults, 20.5% of women reported physical injury since diagnosis, compared to 11.5% of men who had sex with men, and 7.5% of heterosexual men (Zierler et al., cited in De Marco & Johnson, 2003). Kimerling et al. (1999) found in their study that HIV-infected women reported significantly higher rates of criminal victimisation (such as physical assault and completed rape) compared to a demographically comparable non-infected group of women. Thus, women testing positive for HIV infection provoke serious gender issues and conflict, because generally they are afraid to reveal their status to an abusive partner (Lorber, 1997; Scneider, 1992).

Lesch (2000) found in her study of young Coloured women that in their community women were often victimised, hurt and harassed by men. She stated further that women were perceived as powerless and also perceived themselves as powerless in relation to men. According to Heath and Rodway (1999), research studies that focused exclusively on women's psychosocial issues and AIDS found that power and control are central themes. They noted further that these themes traverse the societal and personal context and are also central in the areas of AIDS transmission, education, and healthcare. Cohan and Atwood (1994) stated that the health of women may be jeopardised by public policies that presume infected women can be encouraged to reveal their HIV-positive status to

husbands or intimate partners, even with the stigmatisation and blaming they experience. Consequently, the socio-economic environment must be considered as contributing to discourses on disclosure of HIV/AIDS within which women are disempowered.

The fear of possible rejection was so intense among the women in the present study that some of them felt that they would be shunned and disregarded even on their deathbed:

"Perhaps I am bed-ridden before I die, have to lie in bed perhaps and and sick and suffer I mean. I suffer from sickness and now I'm thinking oh heavens, what will the people say now or what won't they know now. Look she's now suffering from HIV, those are all things I'm thinking of now and…Now I'm thinking they would probably not come close to me when I'm lying there. Nobody will worry or so." (Rosy)

"Ek lê miskien nou voor ek nou dood gaan lê ek nou miskien en en siek en ly nou bedoel ek nou. Ek ly siek en nou dink ek ai jinne wat sal die mense nou sê of wat nou nie weet nie. Kyk sy ly nou aan HIV, dis al wat dinge wat ek nou dink en… Nou dink ek hulle sal seker nie na aan my kom nie as ek nou daar lê nie. Niemand sal worry nie of so." (Rosy)

In developing countries, research studies showed much lower rates of disclosure and more harmful outcomes after disclosure for women (Grinstead et al., 2001). According to Issiaka et al. (2001), disclosure exposes African HIV-infected women, especially when they are disadvantaged and poor, to the risk of isolation on social and financial as well as medical levels. The above narrations of the participants in the present study show that stigmatisation and experiences of rejection may lead to secrecy and isolation, and consequently to not receiving support and care in various areas of their lives. These findings suggest that the discourse of HIV/AIDS also includes the assumption that a woman with HIV/AIDS should keep her illness a secret.

5.2.2.1 Disclosure and effect on children

Many participants in the present study were concerned about their children's feelings and reactions, should they be informed about their mothers' illness. Certain participants mentioned fears of their children being taken away from them, should their HIV-status be known to close family members. A further concern was how family and friends would treat

the children if their HIV-status were disclosed. Maggie struggled with the notion of telling or not telling her young boy of her illness:

"Then I just sit and think…but all I think of are things to do with how I'm going to take it when it comes to that. I mean when the day now comes that I perhaps now, my chance is gone I have to go now. The first thing on which my thoughts fall is my child, then I think of how, how is he going to know one day what is wrong with me. Must I tell him what's wrong with me. Won't it be a disadvantage to him…?" (Maggie)

"Dan sit en dink ek maar aan… maar alles wat ek dink is dinge hoe ek dit gaan vat as dit so kom. Ek bedoel as die dag nou so kom as ek miskien nou, my kans is verby ek moet nou gaan. Eerste waar my gedagte val is my kind, dan dink ek nou aan hoe, hoe gaan hy nou eendag weet wat ek makeer. Moet ek vir hom sê wat ek makeer. Gaan dit nie vir hom 'n nadeel wees nie…?" (Maggie)

According to Broun (1999), women with HIV-infected children experience a particularly tough predicament. Most of the mothers Broun (1999) had seen in therapy expressed feelings of having failed as a mother because they could not protect their children from the negative consequences of this illness. According to Broun (1999), these mothers feared that their children would be rejected and hurt owing to stigmatisation.

Sylvie and Joeyce felt ashamed of being HIV-infected and consequently feared that their children would also be ashamed of their illness:

"Somebody takes me there (the hospital)…and that it will now come out but I am, or say I have a serious sick bed, I become very ill and so. People come to see me and they uh uh discover perhaps that I have um AIDS and so on and…how would my children feel, if they find me they come to me in the hospital…and they had to know I have AIDS…" (Sylvie)

"Iemand bring my daar (die hospitaal)… en dat dit sal nou uitkom maar ek is of ek sê nou ek kry 'n ernstige siek bed of so, ek raak baie siek en so. Die mense kom by my en hulle uh uh vind miskien uit dat ek um VIGS het en so aan en… hoe moet my kinders voel, hulle kom kry vir my hulle kom by my in die hospitaal… en hulle moet weet ek het VIGS…" (Sylvie)

"When I die, my mother will have to tell her (her daughter) what I died of. That I'm HIV+, how is she going to feel." (respondent cries) (Joeyce)

"As ek dood gaan, dan my ma moet vir haar (haar dogter) vertel waaraan ek dood is. Dat ek HIV+ is, hoe moet sy nie voel nie." (respondent huil) (Joeyce)

Maggie related her concern that her son might become scared of her if she told him about her HIV-status:

"...because look, if I now had to tell him (her son) at that age that I've got AIDS, the child will become scared of me." (Maggie)

"...want kyk as ek nou vir hom (haar seun) gaan sê op daardie ouderdom dat ek AIDS het, dan gaan die kind vir my bang raak." (Maggie)

Maggie also feared being isolated from her child, should her mother find out about her illness:

"My mother will also encourage him (her son) not to come to me. So if I tell him now my mother will keep him very far away from me. Because the way she sees it, just one mistake then he can perhaps be touched (infected)... and then she loses a grandchild." (Maggie)

"My ma gaan ook vir hom (haar seun) aanmoedig om nie na my toe te kom nie. So as ek nou vir hom sê sal my ma hom baie ver van my af hou. Want sy vat dit so net een mistake dan kan hy miskien betas (aangesteek) word... en dan verloor sy 'n kleinkind." (Maggie)

According to Nagler et al. (cited in Hackl et al., 1997) mothers often have difficulty discussing their HIV-status with their children and when the child is also infected, discussing the youngster's illness.

Ann and Sylvie stated that they feared that their children would be rejected and victimised should their status be disclosed:

"I'm just scared that my children will be neglected, they won't have friends any longer, won't have playmates. And the people's gossiping... that's what I'm scared of." (Ann)

"Ek is net bang my kinders sal afgeskeep word, hulle gat nie vriende mee het nie, maatjies het nie. En vir die mense se pratery... daarvoor is ek bang." (Ann)

"...but it's hard for me to think I have to suffer from an illness and I can get sick and I can die. And my children or people had to know about it and perhaps throw stones at my children there and so... and how are they going to live with that..." (Sylvie)

"...maar dit is vir my swaar om te dink dat ek moet 'n siekte ly en ek kan siek word en ek kan dood gaan. En my kinders of mense moet daarvan weet en my kinders miskien daar met die klippe gooi en so... en hoe gaan hulle daarmee lewe..." (Sylvie)

Leenerts and Magilvy (2000) also found that the women in their study were often afraid to tell their families or friends. These women were particularly afraid to tell their children, because they feared the children would tell others and that they would be treated

differently or abandoned. In the study conducted by Moneyham et al. (cited in Gaskins, 1991) the mothers worried about negative, possibly harmful responses to their children, as well as the children's inability to keep their mothers' HIV-status confidential. For these women the decision to disclose was situational. In the present study the participants did not verbalise any concerns regarding their children talking to others about their illness, but they were anxious about their children being rejected or victimised by other people should their HIV-status be disclosed. In the above citations of the participants HIV/AIDS is constructed as an illness that is associated with loss and separation, separation from others but also from their own children. This again indicates the discourse of HIV/AIDS as a deadly and shameful illness. Also implicit is the fact that this discourse is not compatible with a discourse of mothering, a discourse within which there is a strong imperative to take care of children and to stay connected to them.

5.2.2.2 Disclosure of child's HIV-status

In the present study certain participants were concerned about their children's HIV-positive status being disclosed. Ann and Nossie respectively said:

"That they (her children) will also perhaps one day, that they also get sick and will die. If one of them had to go before me, then I don't know...But if everybody had to know, the day they have to die... the doctor will tell of course. Then everybody will know my child had HIV and he died from it. But I don't want the doctor to tell, if it had to turn out like this." (Ann)

"Dat hulle (haar kinders) ook miskien eendag, dat hulle ook siek raak en gaan sterf. As een van hulle voor my moet weggaan, dan weet ek nie... Want as almal moet gaan weet, die dag as hulle moet sterwe... die dokter sal mos sê. Dan weet almal mos nou my kind het HIV en hy het daaraan gesterf. Maar ek wil nie hê die dokter moet sê nie, as dit so moet kom nie." (Ann)

"Everybody asks me what is really wrong with my child, why is my child so often sick. I can't tell them, if I were to tell them it would be a whole other business. Then I say no, she has a gastro tummy, the tummy she had that tummy almost from birth... Because I can't tell her (friend) what my child's problem is, because I don't know what kind of answer I'll get from that side." (Nossie)

"Almal vra vir my wat makeer my kind dan werklik, hoekom is my kind so baie siek. Ek kan nie vir hulle gaan sê nie, as ek vir hulle gaan sê dan gaan dit mos nou 'n hele ander besigheid wees. Dan sê ek nee sy het 'n

gastro magie, die magie sy is amper gebore met die magie... Want ek kan nie vir haar (vriendin) gaan sê wat is my kind se probleem nie, want ek weet nie watse antwoord ek gaan kry van daai kant af nie." (Nossie)

The above citations show that the women kept their children's HIV-status a secret because they were cautious and distrustful of the reactions from other people. The participants certainly expected negative reactions, because of the stigma attached to the illness. The HIV-infected mothers who participated in Broun's study also feared that their children with HIV/AIDS would be judged, rejected and even hurt as a result of stigmatisation (1999).

It was clear that the fears mentioned above were not unfounded for the present participants. Elna's daughter, whose HIV-positive status was known to her close family, experienced rejection, contempt and ostracism from certain family members:

"C (her daughter) just approaches the door of the room then C is told, get away from here... you're not coming in and get away from T (her sister's son). I say it's just a child, how it hurts me, my child is chased away from that door like a dog. She's not allowed to go into that room, she may not come near T and they are just children, what do they know what's happening..." (Elna)

"C (haar dogter) kom net by die kamerdeur dan word C gesê, gaan uit hier... jy kom nie in en weg van T (haar suster se seun) af. Ek sê dit is maar net 'n kind, hoe seer kry ek nie, my kind word weggejaag soos 'n hond weg van daai deur af. Sy mag nie in daai kamer in nie, sy mag nie naby T nie en hulle is maar net kinders wat weet hulle wat aangaan..." (Elna)

This atrocious treatment of Elna's daughter caused Elna major psychological distress and pain. She pleaded for her daughter to be seen and treated as an innocent child:

"I feel very bad because I I the way I see it they (her family) can treat me any way they want to, but she doesn't know what's going on around her. She doesn't know she has the sickness. Treat her like a child wants to be treated... how the other children are treated and she is being neglected, she's not treated in the same way." (Elna)"

"Ek voel baie sleg, want ek ek vat dit so hulle (haar familie) kan maar maak met my wat hulle wil, maar sy weet nie wat rondom haar aangaan nie. Sy weet nie sy het die siek nie. Behandel haar soos 'n kind behandel wil word... hoe word die ander kinders behandel en sy word afgeskeep, sy word dan nie so behandel nie." (Elna)

Elna also described feeling judged and rejected by hospital personnel because of her and her child's HIV-status:

"The sisters also know it in the end, because look at the hospital it says in C's (her daughter's) file she's HIV-positive and in the children's ward, the people who are there go through the children's files. Now I go and visit my child and then they'll look at me with a bad... and that's what happens." (Elna)

"Die susters weet dit ook op die ou end, want kyk by die hospitaal in C (haar dogter) se lêer staan sy is HIV positief en in die kindersaal die mense wat daar is hulle gaan die kinders se lêers deur. Nou gaan visit ek my kind en dan kyk hulle my met 'n sleg... en dis wat gebeur." (Elna)

The above narrations prove that the stigma attached to HIV/AIDS does not only pertain to adults, but even children are judged and victimised for being HIV-positive. Leclerc-Madlala (2001) reported that the children living in Kwazulu-Natal's rural areas, who were known to be HIV-positive but had no AIDS-related symptoms, were not welcome in the local schools because they were seen as "unclean". It can be argued then that the illness is constructed as shameful and "bad" regardless of a person's age or the route of infection.

5.2.3 Problems with trust

The majority of the participants in the present study felt that they could not trust close friends and family, their partner or even their mothers with their HIV-diagnosis, because they would not treat the information with confidentiality, sensitivity and respect. Consequently, these participants feared that others would gossip about them:

"Now if I perhaps had to tell somebody else, then then I'll ask that person can I trust you, will you tell nobody. Then he'll say yes you can tell me I won't tell anybody else, but as soon as I turn my back he goes to a chum, have you heard Maggie's got AIDS. Now the chum will Maggie has AIDS... Now I hear perhaps that she tells it to somebody else, then I can't show them before the time that I'm scared or that I feel disappointed...They will look at me in surprise with big eyes, just been talking about her and here she stands. Oh, I don't want to be with her and such things. She wouldn't want to be with me and they'll be scared. They're going to say no no leave that woman alone, that woman is diseased." (Maggie)

"Nou as ek miskien nou vir iemand anders gaan sê, dan dan sal ek nou daai persoon vra kan ek jou vertrou, sal jy vir niemand vertel nie. Dan sal hy nou sê ja jy kan my vertel ek sal vir niemand vertel nie, maar sodra ek my draai dan gat hy na 'n chommie toe, het jy gehoor Maggie het AIDS. Nou gaan die chommie Maggie het AIDS... Nou hoor ek miskien sy vertel dit vir iemand anders, dan gaan ek mos nie voor die tyd vir hulle wys ek skrik of ek voel teleurgesteld nie... Hulle gaan my mos verbaas aan kyk met groot oë, nou net van

haar gepraat en hier staan sy. Oe ek wil nie by haar wees nie en sulke dinge. Sy wil nie by my wees nie en hulle gaan bang wees. Hulle gaan sê nee nee los daai vrou, daai vrou is sieklik." (Maggie)

"One chum will tell the other… say to the other have you heard about this. No, one can't with such things share your secret with people." (Joeyce)
"Een chommie sal vir die ander ene vertel… sê die ander ene het jy gehoor van dit. Nee, mens kan nie met sulke dinge mense in jou geheim deel nie." (Joeyce)

"… my family I don't trust talking to them, because they blab too much… I have felt that there have been um words thrown at me… Even from my husband's mouth… But my eldest sister I'll just never. She will she's a hard woman and when she's angry and so, she wouldn't care about scolding me in front of other people or in the queue. She would never think of my children, what it could do to them…" (Sylvie)
"…my familie ek vertrou hulle nie om met hulle te praat nie, want hulle lap te veel… ek het al gevoel daar was nou al so um woorde wat geslinger is na my toe… Selfs uit my man se mond uit… Maar my oudste suster sal ek net nooit nie. Sy sal sy is 'n harde vrou en wanneer sy kwaad is en so sal sy nie omgee om my voor ander mense uit te skel of in die lyn. Sy sal nooit dink aan my kinders wat dit kan aan hulle doen…" (Sylvie)

"You can take nobody into your confidence, nobody. That why I decided I don't even feel like telling my own mother that it is like this… And perhaps I feel I I've become so ill that it seems I have to tell her, but I just said my prayer and thought she can hear it after I'm gone… when I'm dead, but I don't feel like telling her now." (Hester)
"Jy kan niemand in jou vertroue neem nie, niemand nie. Dit is waarom ek besluit het ek voel nie eers om vir my eie ma te sê nie, dat dit is so nie… En dalk voel ek ek ek het so siek geword lat dit lyk ek moet vir haar sê, maar ek het net my gebed gedoen en gedink sy kan dit maar hoor as ek weg is… as ek dood is, maar ek voel dit nie om vir haar nou te sê nie." (Hester)

"…my boyfriend who gave it to me… my child's father…but today he's dead and I have another boyfriend, but I've never told him… because I'm scared that if he hears it he will perhaps announce it to the people." (Mariana)
"….my boyfriend wat dit vir my gegee het… my kind se pa… maar vandag is hy dood en ek het 'n ander boyfriend, maar ek het hom nooit gesê nie… want ek is bang as hy dit hoor gaan hy dit miskien vir die mense verkondig." (Mariana)

"…because the way I see it it's a private matter, it's a home situation, why do others have to know. Because once others know it will reach other people and so everyone will know about it and um when my dad and I have another falling-out, he'll scold me about it so that everybody has to hear what's going on." (Elna)

"...want ek vat dit so dit is 'n private besigheid, dit is 'n huis situasie, hoekom moet ander weet. Want as ander eers weet dan gaan dit by ander uit kom en so gaan almal weet daarvan en um as ek en my pa weer 'n uitval kry, dan skel hy weer daaroor met my dat almal moet hoor wat gaan aan." (Elna)

From the above narrations it is clear that the participants felt inhibited from sharing their HIV-status with other people, because they were doubtful of others understanding and respecting their dilemma and distress. The participants were fearful of others gossiping about them and this also kept them from disclosing their diagnosis. According to Faithfull (1997), the stigma of HIV/AIDS causes many women to hide their diagnosis, even from close family members. This means that women suffer in isolation on account of the stigma placed on the illness by society and their own communities.

Hester, Maggie and Bertha were the three participants who were the most afraid of telling their mothers of their illness. Hester verbalised a need to trust her mother with her HIV-status, as well as that of her daughter and partner. Regrettably this was not possible, because she knew her mother would not keep her secret to herself:

"But it doesn't come to a point that I have to tell her, because I can't trust her and say mommy... let this stay between mommy and me. She's also mommy's only little girl...grandchild in the house. Let's say I take mommy into my confidence...we tell her that the three of us (she, boyfriend and child) aren't healthy. I can't do that, Elsa...because she can't keep it to herself." (Hester)

"Maar dit kom nie tot 'n punt dat ek vir haar moet sê nie, want ek kan nie vir haar vertrou en sê mammie... lat dit tussen my en mammie bly. Dit is ook mammie se enigste klein meisiekind... nou kleinkind in die huis. Kom ek neem vir mammie in my vertroue in... ons vertel vir haar dat ons drie (sy, mansvriend en kind) nie gesond is nie. Dit kan ek nie doen nie Elsa... omdat sy dit nie vir haarself kan hou nie." (Hester)

Similarly, Bertha did not tell her mother about her illness because of fear that she would tell others, who would then scold her:

"And I haven't told my mother, next day the the people will say I have I have those things. That will be poison, won't it..." (Bertha)

"En toe het ek mos nie vir my ma vertel het nie, oormôre dan sê die mense ek het ek het daai goeters. Dit gat mos gif wees..." (Bertha)

Maggie was anxious that her mother would be reproachful and abandon her. She worried further that her mother would keep her young son away from her:

"She (her mother) knows that I have it, but she wants me to admit it to her and that's what I'm not going to do. Not yet, because it's still too early. It will be a big disadvantage to me, as I told you already... She wants me to tell her myself, but I'm a bit scared... what if she blames me or she throws me away and then I think what will become of my child." (Maggie)

"Sy (haar ma) is bewus daarvan dat ek dit het, maar sy wil hê ek moet dit aan haar erken en dit is wat ek nie gaan doen nie. Nie nou al nie, want dit is nog te vroeg. Dit gaan vir my 'n groot nadeel wees soos ek reeds vir jou gesê het... Sy wil graag hê ek moet vir haar self sê, maar ek is 'n bietjie bang... net nou maar verwyt sy my of sy gooi my weg en dan dink ek wat gaan van my kind word." (Maggie)

Elna, who had disclosed her status to her mother, was very unhappy about her mother telling other people that she was HIV-infected:

"I need their (her parents') support... and they've accepted it, but the problem just was when I told my mother, my mother in turn told other people at work... told neighbours. And I didn't feel happy about that, because the way I see it it's a private matter, it's a home situation, why do others have to know?" (Elna)

"Ek het hulle (haar ouers) ondersteuning nodig... en hulle het dit aanvaar, maar die probleem was net gewees toe ek my ma vertel, het my ma weer vir ander mense vertel by die werk... bure vertel. En ek het nie gelukkig daaroor gevoel nie, want ek vat dit so dit is 'n private besigheid, dit is 'n huis situasie, hoekom moet ander weet?" (Elna)

It is interesting to note from the above narrations that these participants specifically experienced a strong need to trust their mothers as their prime confidantes with their diagnosis, but were too fearful that they would react in a negative way. It seems as if such a reaction from their mothers would have been the ultimate rejection of them as people. Elna's unhappiness about her mother disclosing her status to other people can probably be explained by her disappointment with her mother for being untrustworthy and unreliable. This may suggest that a mother is expected to be someone capable of being trusted with a secret like HIV/AIDS.

However, in a study conducted by Sewpaul and Mahlalela (1998), six of the 15 women participants had disclosed their status to their mothers who, despite the women's fears, were supportive of them. One woman in this study described her entry into a support group, and her subsequent disclosure to all her family members, as the turning point in her life.

In the present study only Joeyce mentioned that her mother accepted her illness, stood up for her when she was judged by others, and gave her adequate support:

"My mother told them but she can drink with you, she can eat from one plate and forks of yours. It's not contagious. You don't have sex with her so that you will get it, my mother explained to her." (Joeyce)

"My ma het vir hulle gesê maar... sy kan drink saam met julle, sy kan eet uit een bord en vurke van julle. Dit is nie aansteeklik nie. Jy gaan mos nie seksueel om met haar dat jy dit gaan kry nie, het my ma vir haar verduidelik." (Joeyce)

Nevertheless, her mother still warned her that should she become ill, she would have to find another place to stay:

"She (her mother) just shook her head (after Joeyce had told her about her illness), she said oh dear, whatever are we going to do? But she told me that if I got ill they would have to put me in another place, because I couldn't stay there." (Joeyce)

"Sy (haar ma) het net haar kop geskud (na Joeyce haar vertel het van haar siekte), sy het gesê ai wat gaan ons tog doen? Maar sy het vir my gesê as ek siek raak moet hulle vir my in 'n ander plek sit, want ek kan nie daar bly nie." (Joeyce)

Sylvie was suspicious and distrustful of people's intentions even when a good word was spoken to her:

"Even if it's not terribly insulting, but it won't um...I won't, even if somebody said a word a good word to me, I will never believe that uh they really mean it." (Sylvie)

"Al is dit nie vreeslik beledigend nie, maar dit sal nie um... ek sal nie, al het iemand vir my 'n woord 'n goeie woord gesê, sal ek nooit daaraan glo dat uh hulle dit regtig bedoel nie." (Sylvie)

Although anxious about disclosing their diagnosis, certain participants expressed the need to share their HIV-status with selected people. Elna decided to share her positive diagnosis with her parents, although she was uncertain and cautious of their reaction:

"But then I worried about it again, must I tell my mom, must I tell my dad, how will they react, how will they treat me and um I just accepted it that I have to tell somebody about it..." (Elna)

"Maar dan het ek weer vir my geworry, moet ek my ma vertel moet ek my pa vertel, hoe gat hulle reageer, hoe gat hulle my behandel en um ek het dit maar aanvaar ek moet iemand vertel daarvan..." (Elna)

Rosy trusted her closest friends with her secret:

"Like the three friends I loved very much. We were like sisters, but because I knew we were very attached to each other like sisters I went and told them..." (Rosy)

"Soos die drie vriende wat ek baie voor lief gewees het. Ons was soos susters, maar omdat ek nou weet omdat ons baie geheg is aan mekaar soos susters het ek mos nou vir hulle vertel..." (Rosy)

The majority of the participants in the present study concealed their status from family, friends and the broader community. Most of the participants expressed a need to share their diagnosis and concerns regarding their condition, but refrained from doing so because they feared harsh judgement, rejection and being talked about. Nevertheless, some participants decided to share their diagnosis with selected people, even when they were unsure about how these people would react.

In the literature it is emphasised that a major concern for women when they have to make decisions regarding disclosure, has to do with trusting another person with their secret. Leenerts and Magilvy (2000) reported that the women in their study mainly used two strategies to cope with their diagnosis, namely hiding (not telling) or selective telling. Hiding the diagnosis involved attempts to conceal the diagnosis as well as denial of the diagnosis. In selective telling women made judgments about whether it was safe to tell others and gambled with themselves about the payoffs and/or costs of disclosing their status. According to these writers, a frequent reason for selective telling was to "stop living a lie", as well as a need to tell previous sexual partners about their exposure to HIV infection (Leenerts & Magilvy, 2000, p.64).

In the present study the participants also used these two strategies, namely hiding and selective telling, to manage their diagnosis. Certain participants like Hester and Bertha did not reveal their illness to anyone, but they were not in denial about their diagnosis. The majority of the participants in the present study used selective telling as coping strategy. None of the participants verbalised a need to tell previous sexual partners, but the majority had disclosed their HIV-status to their partners at the time of diagnosis. Mariana and Bertha were the only two participants who hid their diagnosis from their partners because of fear of abuse.

The citations of the participants show that the illness was constructed as something that someone should be ashamed of and blamed for. The participants expected to be rejected or abandoned should their illness be disclosed. The illness thus became an illness that should be kept a secret, an illness that should not be disclosed.

5.2.4 Consequences of actual HIV disclosure

The participants in the present study who actually did disclose their HIV-positive status to family or friends narrated many experiences of rejection and the loss of relationships, friendships and basic human contact. Thus, the treatment that the participants expected or predicted, namely rejection and abandonment by important others, actually happened to those participants who had disclosed their HIV-status. This shows that the participants' fears of disclosing their status were certainly not unrealistic.

Joeyce felt rejected and shunned because certain family members were afraid that she would infect them. These family members did not want to be physically close to her or touch her. Joeyce actually felt so deserted that she believed that these family members would not even attend her funeral should she die one day:

"My mother and them were shocked. My cousins... it seems they don't want me with them. It seems they're scared I can infect them with the um virus. My mother told them but she can drink with you, she can eat from one plate and forks of yours. It's not contagious. You don't have sex with her so that you will get it, my mother explained to her. I get many rejections from my family. My godmother no longer comes to our house at all since she heard about it. It's now two years that she hasn't been to our house, but she always used to come there over a weekend. I don't believe they will even come to my funeral the day I die." (Joeyce)

"My ma-hulle was geskok gewees. My niggies... dit lyk hulle wil my nie by hulle hê nie. Dit lyk hulle is bang ek kan vir hulle aansteek van die um virus. My ma het vir hulle gesê maar dit, sy kan drink saam met julle, sy kan eet uit een bord en vurke van julle. Dit is nie aansteeklik nie. Jy gaan mos nie seksueel om met haar dat jy dit gaan kry nie, het my ma vir haar verduidelik. Ek kry baie verstote deur my familie. My peetma kom glad nie eers meer by onse huis nie, vandat sy dit gehoor het nie. Dit is nou meer as twee jaar wat sy nie meer daar kom nie, maar sy het altyd oor 'n naweek daarnatoe gekom. Ek glo nie eers hulle sal kom na my begrafnis toe nie die dag as ek dood gaan nie." (Joeyce)

Hester felt so harshly judged by her family that she did not have the freeness or confidence to touch her sister's kids. Although in Hester's case the rejection was not necessarily spoken or overt, she felt it:

"Then I'm so Elsa my sister's children they have babies...Then I feel I want to take the child, I want to go to the children for a bit and pick them up, but then then it just feels to me again their expression on their face shows as if they could have something inside them that they don't want to say. Leave my child alone or something like that." (Hester)

"Dan is ek so Elsa my suster se kinders hulle het babatjies... Dan voel dit vir my ek wil die kind vat, ek wil 'n bietjie na die kinders toe gaan en hulle gaan optel, maar dan dan voel dit net weer vir my hulle uitdrukking op hulle gesig wys so of hulle nou kan iets het in hulle wat hulle nie wil sê nie. Los my kind of so." (Hester)

Elna was verbally ordered to stay away from her sister's child. This harsh and unkind treatment was very painful for her:

"I'm not allowed to touch the child... they told me straight I must stay away from their child. The child may not receive anything from me, unless it's a closed thing... then they'll still take it, but something that's open that I'm eating from or if I just open a banana, then I may not break off a piece for him... But I'm not allowed to pick up the child and nothing, but I feel hurt about it but I accept it like that, I just accept it." (Elna)

"Ek mag nie aan die kind raak nie... hulle het vir my straight gesê ek moet wegbly van hulle kind af. Die kind mag niks van my ontvang nie, tensy dit 'n toe ding is... dan sal hulle dit nog vat, maar wat oop is wat ek nou van eet of ek maak nou net 'n piesang oop, dan mag ek nie vir hom afbreek daarvan nie... Maar ek mag nie die kind optel nie en niks nie, maar ek voel seer daaroor maar ek aanvaar dit maar so, ek aanvaar dit maar." (Elna)

The above quotations clearly show the ignorance of people regarding the transmission of HIV. These participants, like many other women infected with HIV/AIDS, were rejected by and physically and emotionally isolated from close family and friends on a daily basis. Their experiences show that the participants' understanding of HIV/AIDS, as shameful and blameworthy, was indeed widely shared in their communities and that people treated HIV-infected persons accordingly.

Elna described further how she was prohibited from preparing food for her family, because of a certain member's fear of becoming infected with the virus. Elna surprisingly, did not

express anger at being treated so unfairly, but verbalised pain and dissatisfaction with her situation:

"... he (sister's boyfriend) doesn't eat from my hands. That's why when I buy food she'll rather ask me if she can't make the food... Now I feel very bad about that, then I said to mommy, mommy should rather make the food, then at least I know he will eat with us. Even if he knows it's my food he'll eat with us if somebody else makes it, but if I made it then he doesn't eat it."(Elna)

"...hy (suster se mansvriend) eet nie uit my hande uit nie. Daarom as ek kos koop dan sal sy my eider vra of sy nie die kos kan maak nie... Nou ek voel baie sleg daaroor, toe sê ek vir mammie, maak mammie maar eider kos, dan weet ek mos nou hy gaan saam eet. Al weet hy dit is my kos sal hy saam eet as iemand anders dit maak, maar as ek gemaak het dan eet hy dit nie." (Elna)

Rosy regretted disclosing her HIV-status to her closest friends, as these friends turned away from her:

"They're too scared to touch me or so...Like the three friends I loved very much. We were like sisters...And later they didn't care about me any more...they no longer come to chat as usual... Now I feel bad and I think afterwards, oh heavens, why did I tell them." (Rosy)

"Hulle is te bang om so of aan my te vat of so... Soos die drie vriende wat ek baie voor lief gewees het. Ons was soos susters... En later van tyd het hulle nie meer geworry oor my nie... hulle kom gesels nie meer soos gewoonlik nie... Nou voel ek sleg en dan dink ek agterna, ai jinne hoekom het ek nou vir hulle gesê." (Rosy)

Elna and her HIV-positive daughter also experienced rejection from a close neighbour:

"They don't want to come into contact with you, because um in my case this is what it's like when I heard for the first time that my mother had told the woman next door...Then the woman next door no longer came to the top, after she heard I was like that...She used to be very fond of C (her daughter), but she no longer cares about C." (Elna)

"Hulle wil nie in aanraking met jou kom nie, want um by my is dit so toe ek nou vir die eerste keer gehoor het my ma nou vir die buurvrou vertel het... Toe begin die buurvrou nie meer bo kom nie, nadat sy gehoor het ek is so... Sy was baie oor C (haar dogter) gewees, maar sy is nie nou meer oor C nie." (Elna)

Nossie stated that her partner reacted with anger when she told him that she was HIV-positive:

"...when I came to tell him (her child's father), doctor asks if you don't want to come and get tested, because my child and I are HIV. Then he was angry with me and from that time, Elsa, from that time he has been living with anger towards me." (Nossie)

"...toe ek vir hom (haar kind se pa) kom sê het, dokter vra of jy nie vir jou wil kom toets nie, want ek en my kind is HIV. Toe is hy kwaad vir my en van daar af Elsa, van daar af lewe hy so kwaad vir my." (Nossie)

Sylvie was very upset when she heard that her estranged husband had told friends that she would never be able to have an intimate relationship with any man again, because she would be responsible for that person's death:

"...then he said yes I uh would never be able to have a man, because it uh would be a man's death sentence and that type of thing...that I have AIDS, that's what I heard from a female friend of mine." (Sylvie)

"...dan het hy gesê ja ek uh sal nooit kan 'n man vat nie, want dit uh sal 'n man se dood sentence wees en die tipe van dinge... dat ek VIGS het, dit is wat ek by 'n vriendin van my gehoor het." (Sylvie)

Sonja was one of the few participants who trusted her partner not to tell others about her illness:

"I can talk to him he won't tell anybody else...because I told him it stays just between us..." (Sonja)

"Ek kan praat met hom hy sal nog nie iemand anders vertel nie... want ek het vir hom gesê dit bly net tussen ons..." (Sonja)

The consequences of stigmatisation and disclosure also had practical implications for some of the participants. Joeyce was ordered to leave her home after disclosing her status. Hester's husband repeatedly lost his job and, consequently, his income following disclosures to his employers:

"And the same evening he (farm-owner) called all the farm people together and then he told them about it. And that's why the people, they look at me with that attention, but they won't talk about it, they may not talk about it. And now one afternoon he just stops next to me. He stops then he says, Joeyce he says... just make sure that you pack your clothes now I'm standing here and be off, please. I'm not really allowed to stay there." (Joeyce)

"En dieselfde aand toe het hy (plaaseienaar) al die plaasmense bymekaar kom en toe het hy dit vir hulle vertel. En dit daarom dat die mense, hulle kyk my met daai aandag, maar hulle sal nie daaroor praat nie, hulle mag nie daaroor praat nie. En nou een middag toe stop hy net by my. Stop hy toe sê hy, Joeyce sê hy... sorg net dat jy jou klere nou pak ek staan hierso en maak dat jy wegkom asseblief. Ek mag nie eintlik daar bly nie." (Joeyce)

"And he says each time he (her husband) goes to work also, it bothers him and he doesn't feel like telling that farmer or telling that mister that he has the sickness. Now if he gets hurt then what must he do and then he gets chased away. It has happened many times... he doesn't keep a job... He (her husband) carried

on on his own, worked with the mister. And the time that he cut himself and when my child started getting so seriously ill, that was the time that he also told the mister. I went with him, what was that mister's response…I don't have any more work for him, but just now he was still sitting there working. It feels to me like a slap in my face." (Hester)

"En hy sê elke keer as hy (haar man) gaan werk ook, dan dit pla vir hom en hy voel nie om vir daai boer te sê of vir daai meneer te sê dat hy die siek het nie. Nou kry hy seer dan hoe moet hy maak en dan word hy weggejaag. Dit het al baie kere gebeur… hy hou nie 'n werk nie… Hy (haar man) het op sy eie aangegaan met die meneer gewerk. En die tyd toe hy nou vir hom raak sny en toe my kind so ernstig beginne siek raak, toe is dit nou die tyd wat hy ook nou die meneer gesê het. Ek het saam met hom gegaan, wat was daai meneer se antwoord… ek het nie meer werk vir hom nie, maar hy was nou nog besig om te sit en werk. Dit voel vir my soos 'n klap in my gesig." (Hester)

Verbal abuse that was feared by most participants actually happened to all the participants in the recent study who had disclosed their HIV-status. This caused them extreme emotional pain:

"To think it's through me, I gave it to him (her boyfriend)… Sometimes he says to me when he scolds me so badly, it's because of you, you have shortened my life…" (Joeyce)

"*Om te dink dit is deur my ek het dit vir hom (haar mansvriend) gegee… Partykeers dan sê hy vir my as hy my so lelik uitskel, dis hoeka deur jou, jy het my lewe verkort…" (Joeyce)*

"Now they are hitting again, they are again throwing the illness back in my face. And that is what hurts me, but I avoid such things I avoid it because I don't want to think about it." (Elna)

"Nou slaan hulle weer, hulle gooi alweer my siekte terug in my gesig in. En dit is wat my seermaak, maar ek vermy sulke goed ek vermy dit, want ek wil nie dink daaraan nie." (Elna)

"I don't want people to be scared of me sister (subject cries) and scold me, because it happened to me down there at home, my brother told me I was an AIDS sufferer…Then I just went into my room, then I cried myself to sleep…" (Mariana)

"Ek wil nie hê mense moet bang wees vir my nie suster (subjek huil), en my uitskel nie, want dit het daar onder by die huis gebeur met my, my broer het my gesê ek is 'n vigsleier… Toe gaan ek maar in my kamer toe, toe gaan huil ek my aan die slaap…" (Mariana)

"And the day that she (her female friend) came in from um alcohol and um then she gave me such a bad scolding … I felt very hurt but I still argued I told her I didn't have that illness…" (Sonja)

"En die dag toe sy (haar vriendin) inkom van um alkohol en um toe skel sy omtrent vir my lelik uit… Ek het baie seer gevoel, maar ek het nog altyd gestry ek het vir haar gesê ek het nie daai siekte nie…" (Sonja)

"In their whole attitude I can see they want to be a bit a bit away from me. Or not wash with me out of the same thing or do something like that… they're away from me. They don't want to drink with me from a cup of water or such. Because since my brother scolded so about the AIDS, it feels to me very… then I should rather not communicate with people." (Hester)

"In hulle hele houding kan ek sien hulle wil 'n bietjie 'n bietjie weg van my af wees. Of saam met my in een ding uit was of so maak nie… hulle is weg van my af. Hulle wil nie saam met my uit 'n koppie water drink of so nie. Want van my broer so geskel het oor die VIGS, voel dit vir my baie… dan moet ek maar nie met mense kommunikeer nie." (Hester)

"Then I feel so bad about myself, so sad when I talk to them… Then I leave everything, then I turn round then they scold me. Then I don't worry…"(Bertha)

"Dan voel ek so sleg oor myself, so hartseer as ek met hulle praat… Dan los ek als af, dan draai ek om dan skel hulle vir my uit. Dan worry ek nie…" (Bertha)

The possible negative consequences of trusting others and disclosing an HIV-positive diagnosis are clearly demonstrated in the above citations. In the above situations some women were scolded and others blatantly condemned by close family members or friends. All the participants expressed feelings of pain and distress at being treated in such an inhumane manner by people close to them. These experiences of victimisation and rejection seem to be informed by an understanding that people who are HIV-infected are blameworthy and "bad".

Joeyce had an experience where she heard a political party leader in her community comment that people with HIV/AIDS should be voted out of the community, which most probably meant that HIV-infected people should live apart from non-infected people:

"Then I come past, then he (ANC chairman) just carries on, he just carries on, hey my brother um um the AIDS thrash must be voted out of the place. Then I was wondering…" (Joeyce)

"Verder kom ek verby, verder sak hy (ANC voorsitter) net so af, sak hy net so af, hê my broer um um die VIGS-goed moet uit die plek uit gevote raak. Toe wonder ek nou…" (Joeyce)

It was clear that there was a serious lack of understanding and compassion in their community for the participants in the present study. Hester was even accused of having special rights and unfair financial benefits; because of being ill with AIDS she received a disability grant from the state:

"Others say I get a house because I have AIDS. Others say I pay (disability grant) because I have AIDS, I don't have TB." (Hester)

"Ander sê ek kry 'n huis omdat ek VIGS het. Ander sê ek pay (ongeskiktheidstoelae) omdat ek VIGS het, ek het nie TB nie." (Hester)

Camlin and Chimbwete (2003) stated that disclosure of an HIV-positive status is highly stigmatised in South Africa. According to Hackl et al. (1997), women who share their HIV/AIDS diagnosis with family or friends risk stigmatisation (including reactions of fear, shock and blame), isolation (because of others' fears of casual transmission and the possibility of desertion), and potential loss of self-esteem (lack of confidence and self-blame). O'Hea, Sytsma, Copeland and Brantley (2001) noted that stigma might lead to a variety of negative consequences and losses such as social isolation, job termination, housing difficulty, and negligent care by medical professionals and caregivers.

As has been found in the present study, the most important reasons for women being cautious to disclose their HIV-positive status are: being blamed for their illness, stigma, shame, and fear of judgment and rejection (Gaskins, 1999; Hudson et al., 2003; Issiaka et al., 2001; Morrow et al., 2001; O'Hea et al., 2001; Richardson et al., 2001; Schlebush & Cassidy, 1995; Withell, 2000). In other words, given a discourse within which HIV/AIDS is constructed as an illness to be ashamed of or to be blamed for, people with HIV/AIDS will understandably respond by keeping their status a secret.

5.2.5 Summary

All of the participants in the present study were extremely conscious of the stigma attached to HIV/AIDS and the harmful consequences of disclosure. The participants narrated their fear of many losses should they disclose their status, inter alia, loss of relationships with important others, loss of respect, acceptance and love, loss of motherhood and caring for their children, loss of family support and of community and social life. Therefore, the majority of the participants in the present study concealed their status from close family, friends and the broader community. Those participants in the

present study who did disclose their HIV-status or whose status became known to others experienced many of these losses, for the reason that they were harshly judged and frequently rejected / abandoned by family and friends and in some instances by neighbours and members of their community. Thus, it can be said that for the participants in the present study HIV/AIDS was as an illness of silence, an illness of separation, and an illness of loss.

Discourses found thus far in the participants' accounts of living with HIV/AIDS are: a discourse of HIV/AIDS as a deadly illness, an illness that a person should be ashamed of and be blamed for; and discourses of silence, separation, and loss. It therefore seems that a discourse of shame and blame implied a discourse of silence. It can be argued then that these discourses differentiate HIV/AIDS from most other chronic and fatal illnesses.

The stigma attached to HIV/AIDS can also be ascribed to the disabling effect it has on the body and the various opportunistic illness conditions and infections that can develop as the body's immune system is attacked by HIV. Consequently, the illness symptoms and the effect on physical appearance cause women with HIV/AIDS severe psychological distress. The next section will focus on the illness symptoms experienced by the participants in the present study as well as the influence of these symptoms on the psychosocial functioning of these women.

5.3 Distress regarding physical condition and illness symptoms

All the participants in the present study described numerous illness symptoms, which caused them physical and psychological suffering and pain. The most prominent physical symptoms that emerged during the qualitative interviews were fatigue, pain and weight loss. In the section on health-related items in the interview schedule (Addendum C1, p.361), the participants were presented with an open-ended question enquiring about physical symptoms related to or caused by their illness. Fatigue, vaginal infections and anxiety-related symptoms were reported most frequently. Pain and weight loss were also

regularly mentioned. Anxiety-related symptoms were mostly described in physical terms, such as trembling, dizziness, tightness in the chest and panic attacks. In the qualitative interviews and the questionnaire on health-related items, the participants who had been diagnosed for more than a year (Sylvie, Elna, Joeyce, Hester and Rosy) verbalised more severe illness symptoms, as well as additional symptoms such as painful glands and sores.

Melnick et al. (cited in Van Servellen, Aguirre, Sarna & Brecht, 2002) stated that once HIV-infected, women may be at greater risk for illness-related morbidity and adverse outcomes than men. As a woman's immune system declines, she may be living with numerous chronic illnesses. As stated in the literature review (Addendum A, p.313) women experience certain clinical manifestations that are unique to them or more prevalent than in men. Women have been reported to have more severe distress from specific HIV-related symptoms, for instance pain, fatigue and gynaecological conditions (Breibart et al., cited in Van Servellen, Aguirre, Sarna & Brecht, 2002).

5.3.1 Weight loss

In the questionnaire on health-related items, five out of the 11 participants reported weight loss when asked about physical symptoms related to or caused by their illness. In the qualitative interviews weight loss was also one of the visible symptoms of AIDS frequently brought up by the participants. Weight loss can be regarded as one of the primary illness symptoms that caused the participants in the present study a great deal of physical and emotional distress.

Rosy narrated how her fluctuating weight influenced her thoughts regarding her HIV-status. When she gained weight, she hoped that it was a sign of her not really being infected with HIV:

"Sometimes I ask myself, oh dear do I really have to have HIV or so. Are the doctors not perhaps making a mistake or what, then sometimes I pick up weight and sometimes I'm thin again…and then I look then I just talk to myself in the mirror about whether I now really have HIV…" (Rosy)

"Somtyds dan vra ek vir myself, ai moet ek rêrig HIV hê of so. Maak die dokters nie miskien 'n fout of wat nie, dan somtyds tel ek gewig op en somtyds is ek weer maer... en dan kyk ek so dan praat ek sommer in die spieël met myself of ek nou rêrig HIV het..." (Rosy)

Hester related how her loss of body weight was concomitant with becoming seriously ill and losing all hope of recovering:

"It was a bit hard, because my child later, we didn't put on weight. And I became seriously ill, I couldn't walk and I just felt it is the end for me." (Hester)

"Dit was 'n bietjie moeilik gewees, want my kind het later, ons het nie opgetel nie. En ek het ernstig siek geraak, ek kon nie geloop het nie en ek het net gevoel vir my is dit my einde." (Hester)

Some participants felt anxious about others guessing their HIV-diagnosis because of their vissible weight loss:

"...and I still wonder from day to day what I really look like. Can someone see from looking at me that I have AIDS or so, I wonder from day to day if someone can see it on me..." (Sylvie)

"...en ek wonder nog van dag tot dag hoe lyk ek regtig. Kan iemand aan my sien dat ek VIGS het of so, ek wonder van dag tot dag of iemand dit kan aan my sien..." (Sylvie)

"... and I became thin and so on...which is the problem and so. Then I didn't know what to say, because I was scared people would discover there is something serious...People become suspicious or they think anything or many times people also just say anything and...so I was too scared to speak to somebody..." (Sylvie)

"... ek het maer geword en so aan... wat die probleem is en so. Dan het ek nie geweet wat om te sê nie, want ek was bang mense kom agter daar is iets ernstigs... Mense word agterdogtig of hulle dink enigiets of baie kere dan sê mense ook sommer enigiets en... so ek was te bang om met iemand te praat..." (Sylvie)

"And friends see I'm getting thin, they would like to know what's the matter with me, but I'm not going to tell them I have AIDS." (Maggie)

"En vrinne sien ek raak skraal, hulle wil graag weet wat makeer ek, maar ek gaan nie vir hulle vertel ek het AIDS nie." (Maggie)

Elna tried to conceal the real cause of her weight loss as follows:

"...then they (her friends) always tell me, but you are you are thin hey, and are you ill. Then I say no, I just have a few problems and my child doesn't want to let go of the breasts and that's why I stay so thin." (Elna)

"...dan sal hulle (haar vriende) altyd vir my sê, maar jy is jy is dam maer en is jy siek. Dan sê ek nee ek het net maar bietjie probleme en my kind wil nie die borste los nie en dis hoekom ek so skraal bly." (Elna)

The above citations show that the physical disfigurement associated with AIDS, such as severe weight loss, caused the participants in the present study to fear that others would guess their diagnosis and then reject or abandon them. The participants' experiences and feelings seem to be informed by an understanding that HIV/AIDS is an illness that causes serious weight loss. In the literature this is a very common concern for HIV-infected women from different cultures, because weight loss is a visible illness symptom universally associated with having AIDS. According to De Cock (cited in Withell, 2000), the everyday term for AIDS in Uganda and other African countries is "slim" disease because of the progressive weight loss in advanced AIDS. In the literature it is emphasised that the visible symptoms of AIDS, especially weight loss, cause considerable distress to sufferers who dread that others will suspect their diagnosis and then reject and isolate them (Sowell et al., cited in Sarna et al., 1999; Withell, 2000).

5.3.2 Fatigue

In the questionnaire focusing on health-related items, fatigue was reported by six participants. In the qualitative interviews, tiredness and weakness were illness symptoms frequently mentioned by the participants:

"Um let's say one day I just feel um so many times then I just feel I'm now too tired. I um cannot work any longer. I just want to finish now. I have felt many times, but I just have to, what what am I going to do if I had to give up my work. I can no longer, there are some days that I come from my work then I can't get up. Or I go to lie on my bed then I can't really get up...." (Sylvie)

"Um so sê maar op 'n dag voel ek net um so baie kere dan voel ek net ek is nou te moeg. Ek um kan nie meer werk nie, ek wil nou net klaar maak. Ek het al baie kere gevoel, maar ek moet maar, wat wat gaan ek dan doen as ek my werk sou opgee. Ek kan nie meer nie, daar is party dae wat ek uit my werk uit kom dan kan ek nie opstaan nie. Of ek gaan op my bed gaan lê dan kan ek nie regtig opstaan nie..." (Sylvie)

"Then I make her (her daughter's) porridge for the morning and then I start with my washing or I wash or then I sit again for a little while when I get so tired..." (Rosy)

"Dan maak ek nou haar (haar dogter) pap vir die oggend en dan begin ek met my wasgoedjies of ek was of dan sit ek weer so 'n tydjie as ek so moeg raak..." (Rosy)

"Then I feel tired, I really feel tired like someone like someone has beaten me, I feel tired like that. Then I wet my face…I think of the illness, that I'm so weak. I think of everything inside myself and then I feel so tired…" (Bertha)

"Dan voel ek moeg, ek voel rêrig moeg soos een wat soos een wat my geslaan het, so voel ek moeg. Dan maak ek my gesig nat... Ek dink om die siekte, dat ek so swak is. Dink ek als in my in en dan voel ek so moeg…" (Bertha)

In the literature, fatigue is reported regularly by HIV-infected women under study and is commonly seen as a warning sign that progression of disease and disability are taking place (Rose et al., cited in Hudson et al., 2003). As anticipated, because of the entry requirements for the presence of HIV-related illness symptoms in the study conducted by Sarna et al. (1999), a variety of physical disruptions, especially the predominance of severe fatigue and pain and the consistent nature of these disruptions over time, were reported. According to Lee et al. (cited in Hudson et al., 2003), parenting adds to the experience of higher morning fatigue, because most women with symptomatic HIV infection, like the participants in the present study, are low-income women with young children. The high levels of fatigue experienced by the participants in this study had a negative effect on their daily functioning, their productivity and performance at home and at the workplace. Their experiences of fatigue and the loss of physical strength may suggest that they were failing to be the primary caregivers and homemakers that they were expected to be in their communities. The effect of fatigue and weakness on the daily functioning of the participants will be discussed in more detail in this chapter under section 5.4.2.2.

5.3.3 Pain

During the qualitative interviews a number of participants described their experience of severe pain and discomfort:

"It's just sometimes that I get the pains behind my shoulder blades. Sometimes it's gone then it comes again. When I have been lying down, I must first turn to get up. Then it's the pain here below my kidneys that hurts me so. And I also can't wear anything that's tight around my stomach, then my stomach starts to pain. Then it almost looks as if lumps are forming here, here on either side of my stomach." (Joeyce)

"Dit is net partykeers dat ek die pyne agter my blaaie kry. Partykeers is dit weg dan kom dit weer. Nou as ek so gelê het dan moet ek eers draai om op te staan. Dan is dit die pyn hier onder my niere wat my so seer maak. En ek kan ook nie iets dra wat styf is om my maag nie, dan begin my maag te pyn. Dan lyk dit amper hier maak sulke knoppe, hier alkant my maag." (Joeyce)

"I just feel sister it's just down here…Then I think it's something tapping me like that, then it's not that, then it's such a weak pain going down here. Such pain…sore, sore, my whole body. I feel it here behind in my back…" (Bertha)

"Ek voel net suster dis net hier af… Dan dink ek dis iets wat my so tik, dan is dit nie daai nie dan is dit so swak pyn hier af. So pyn… seer seer, my hele liggaam. Voel ek hier agter my rug…" (Bertha)

In the questionnaire on health-related items two participants, Elna and Rosy, mentioned that they suffered from recurring headaches. During the qualitative interviews three other participants, Ann, Bertha and Hester, narrated that they suffered from headaches:

"Oh I said the other day I have stress…I can't, everything works on me…if the day is too full…I get headaches. It's not really that the little one cries, but now the others still come with their…it's these and those little things, but actually it's the little one that mostly keeps me busy." (Ann)

"O ek het nou die dag gesê ek het stres… ek kan nie, dit werk alles op my… as die dag te vol is… ek kry kopsere. Dit is nie eintlik dat die kleintjie huil nie, maar nou kom die anders nog met hulle… dit is dit en daai dingetjies, maar eintlik is dit die kleintjie wat my die besigste hou." (Ann)

"Last night just as I lay down my head was so sore…my whole body. I did washing yesterday. I didn't actually I didn't wash I just took the things from the washing machine… I felt tired, but my head is still aching now…" (Bertha)

"Gisteraand net soos ek lê is my kop so seer… my hele liggaam. Ek het mos nou gister gewas. Ek het eintlik nie ek het nie gewas nie ek het net die goed uit die wasmasjien uit gehaal… Voel ek moeg, maar my kop is nou nog seer…" (Bertha)

"How can I tell Elsa what I feel like, the moment I feel a bit tired then I also think about it. Or when my head aches then I think again of the sickness." (Hester)

"Hoe kan ek vir Elsa sê hoe ek voel, die moment as ek 'n bietjie moeg voel dan dink ek ook daaroor. Of as my kop pyn dan dink ek weer aan die siek." (Hester)

The above data correspond with symptom experience of women with HIV/AIDS that has been documented in a number of research studies. In the study of Hudson et al. (2003), women reported muscle weakness, headaches and joint pain as their most prevalent

symptoms. Sarna et al. (cited in Hudson et al., 2003) found similar results, with a majority of their respondents reporting fatigue, pain and difficulty doing physical work.

Withell (2000) also reported that physical pain and suffering were acknowledged by participants and endured with dignity, but perseverance to keep going was at times needed. Vosvick, Koopman, Gore-Felton, Thoresen, Krumboltz and Spiegel (2003) found that pain was associated with decreased energy, physical functioning, social functioning, and role functioning. According to Hudson et al. (2003), Rosenfeld et al. (cited in Sarna et al., 1999) and Vosvick et al. (2003), pain as well as the severity of symptoms have been significantly related to psychological well-being and quality of life. The participants' descriptions show that the illness caused them extreme physical suffering and pain that negatively influenced their daily performance. These experiences of weight loss, pain and exhaustion seem to be further enhanced by a notion that a woman in their communities should be energetic and productive at home.

5.3.4 Gynaecological symptoms

In the questionnaire on health-related items vaginal infections were reported by five of the participants. Other gynaecological symptoms mentioned by the participants were sores and moles in the vaginal area (three participants), bladder infections (two participants), and abnormal menstruation (one participant). During the qualitative interviews vaginal infectons were also described by certain participants. Maggie narrated that she suffered from recurring vaginal infections:

"Each time I came to the clinic with the same problem (vaginal infection). They gave me treatment for it, they warned me against it." (Maggie)

"Elke keer kom ek met dieselfde problem (vaginale infeksie) by die kliniek. Hulle gee vir my behandeling daarvoor, hulle waarsku my daarteen." (Maggie)

Many research studies revealed that recurring vaginal candidiasis and other gynaecological symptoms are the most common initial manifestation of HIV infection in women (Berman, 1993; Hudson et al., 2003). In a study conducted by Frankel et al. (cited in Hudson et al.,

2003), it was found that 66% of the HIV-infected women had gynaecological symptoms, such as abnormal vaginal discharge, vaginal pruritis and pelvic pain. Hudson et al. (2003) reported that the high prevalence of gynaecological symptoms in their sub-sample of respondents was consistent with the above results. According to Hudson et al. (2003), these findings were significant because it is known that women postpone seeking healthcare and are mostly diagnosed with gynaecologic-related AIDS-defining conditions. They stated further that symptom distress, or the degree to which symptoms are bothersome, is frequently the motivation for women to seek care. However, according to these writers, this condition does not always prompt HIV testing for women. Berman (1993) and Hudson et al. (2003) argued that with the recognition of the importance of earlier treatment of HIV infection, and the knowledge that recurrent vaginal candidiasis is apt to be the earliest clinical manifestation in women, better educational efforts directed at both healthcare professionals and laypersons are of vital importance.

5.3.5 Anxiety-related symptoms

In the questionnaire on health-related items, five participants reported anxiety symptoms such as dizziness, trembling or shaking, sweating and chest discomfort. Shortness of breath and sweating are symptoms that have been mentioned in many other research studies. Two of the participants in the present study mentioned that they experienced panic attacks on a regular basis. Joeyce, who was one of the three participants diagnosed with HIV for the longest period of time, experienced auditory hallucinations from time to time. Because of the researcher being aware of Joeyce's alcohol abuse problem, it was unclear to what extent the effects of alcohol contributed to these symptoms. Joeyce visited the Stellenbosch Hospice on a regular basis for medical treatment and counselling. During many of these visits Joeyce was intoxicated. Alcohol abuse was a problem for most of the participants and was used as a form of avoidance and escapism to cope with their illness condition. This problem is discussed in more detail in section 5.6.2.

5.3.6 Other illness symptoms

Besides the more prevalent symptoms such as weight loss, fatigue, pain and vaginal infections, some participants revealed additional symptoms that caused them physical and emotional distress. Other physical symptoms elicited by the open-ended question in the questionnaire on health-related items were sores and moles on the body, i.e. face and under arms (two participants), increased perspiration (two participants), blurry eyes / vision (one participant), and hypersomnia (one participant).

At the time of the interview only one participant, Hester, was receiving treatment for tuberculosis (TB), and she was also one of the participants with the most serious physical illness condition. According to Wilson (2002), HIV infection is the most potent known risk factor for TB. He stated further that in HIV-infected individuals undiagnosed TB leads to prolonged morbidity and is one of the most common causes of death. The study conducted by Zuyderduin (2004) revealed that HIV-positive women with TB needed special attention and support to cope with the double stigma associated with both illnesses.

Joeyce revealed an illness episode which caused her body to become extremely weak. She stated her experience and feelings as follows:

"I'm just scared that it could happen to me again, of the blood that I vomited, I really thought I was dying. I couldnt sleep, I had to sit upright the whole night just like that with the cloth and the bath in front of me. Then later I was weakly, weakly, weakly, weakly ill." (Joeyce)

"Ek is net bang dat ek dit weer kan oorkom, vir die bloed wat ek opgegooi het, ek het rêrig gedink ek gaan dood. Ek kan nie slaap nie, ek moet heel nag regop sit sommer so met die lap en die bad voor my. Toe het ek later van tyd was ek swak, swak, swak, swak siek gewees." (Joeyce)

In the questionnaire on health-related items, swollen and painful glands were reported by three participants. During the qualitative interviews two of the same participants, Elna and Hester, complained about painful sores and glands which caused them severe discomfort:

"But now it's again the eyes the eye and the lips and then the the boils that I get. Now um last week I didn't walk at all, because it's on my hip and it just got so swollen last night then I just had to lie lie lie." (Elna)

"Maar nou is dit nou weer die oë die oog en die lippe en dan die die swere wat ek kry. Nou um ek nou vir verlede week glad nie geloop het nie, want dit is op my heup en dit het net so geswel gisteraand toe moet ek nou net lê lê lê." (Elna)

"I have a serious problem, the glands, pimples and sores and things under my armpits here below and on the lower part of my body. Now what must I do then. It's a question in my life that I ask myself many times. What must I do to get myself healed, but I try my best to get these little pimples healed. But when I look again, then they are just such big lumps once more..." (Hester)

"Ek het 'n ernstige probleem, die kliere, puisies en sere en goed onder my blaaie hier onder my en aan my onderlyf. Nou wat moet ek dan doen. Dit is 'n vraag in my lewe wat ek my baie keer self af vra. Wat moet ek doen om my gesond te kry, maar ek probeer my bes om hierdie puisietjies gesond te maak. As ek net weer sien dan staan hulle maar net weer sulke knoppe..." (Hester)

It is clear from the citations of the participants that the pain and discomfort of their illness symptoms, as well as the management and treatment of these symptoms, caused them severe physical and psychological distress.

5.3.7 Management of illness symptoms of self and others

Hester was one of the five participants who had been diagnosed with HIV for one year or more. These participants experienced more illness symptoms (see Chapter 4, Table 2, p.69) that caused them acute physical and psychological distress. Prior to the research interview Hester had to be hospitalised for her TB condition and visited the day clinic and hospital regularly for treatment of her AIDS-related illnesses and opportunistic infections. Hester recounted her utter despair, feelings of hopelessness and sense of futility regarding the management and treatment of her illness symptoms, in a very descriptive manner:

"Or it doesn't help, because each time they cut the thing out and then it just comes out again in another place or in the same place and each time the soreness just goes on goes on goes on. ..The question I also want to ask Elsa is about the sores that occur in the lower part of my body and occur under my armpits. How is it, when will they ever disappear, or do they now go together with the HIV or are they just things that come out? " (Hester)

"Of dit help nie, want dan hulle sny dan elke keer die ding uit en dan kom hy net op 'n ander plek dan uit of op die dieselfde plek en elke tyd die seer gaan net aan al hoe aan al hoe aan...Die vraag wat ek ook vir Elsa

wil vra is, die sere wat in my onderliggaam voorkom en onder my blaaie voorkom. Hoe is dit wanneer sal dit eendag kan weggaan of gaan dit nou gepaard met die HIV of is dit net goete wat uitkom?" (Hester)

"...but it just feels to me that things aren't going to change. Must I still every day every, I get despondent... keep on being ill I don't get well. What more do I then have to do, I try my best, I take my pills, I use ointment and things I get from the clinic, but but nothing helps." (Hester)
"...maar dit voel net vir my dinge gaan nie verander nie. Moet ek dan nog elke dag elke, ek raak moedeloos... bly aant siek ek raak nie gesond nie. Wat moet ek dan nou nog doen, ek probeer my bes, ek gebruik my pille, ek gebruik salf en goeters wat ek kry by die kliniek, maar maar niks help dan nie." (Hester)

The above citation shows that Hester, throughout her suffering and distress caused by her physical illness symptoms, strove to regain a healthy body.

Hester acknowledged that HIV hinders the normal healing process:
"...But this I know Elsa it's because we are HIV-positive that our sores take much longer than usual to heal." (Hester)
"...maar dit weet ek Elsa omdat ons nou HIV positief is, is dit dat ons seerplekke baie langer neem as gewoonweg om gesond te raak." (Hester)

Since medical treatment was unsuccessful and caused Hester extreme physical pain, she developed a fear of further treatment:
"When I go to a doctor and the doctor tells me take off your clothes, then I already feel scared. It feels to me as if I I should run away, because I don't know what they're going to do now... I think the reason why I'm so scared of a doctor, Elsa, is because I have so much soreness and then I go to the doctor, the things the sores are cut out and they don't get well. It just feels to me that the doctors are making it worse, that it's getting more and more sore." (Hester)
"As ek by 'n dokter kom en die dokter sê vir my, trek vir jou uit dan voel ek klaar bang. Dit voel vir my ek ek moet weghardloop, want ek weet nie wat hulle nou gaan maak nie... Ek dink die rede hoekom ek so bang is vir 'n dokter Elsa, dit is seker omdat ek so baie seer het en dan gaan ek na die dokter toe, die goed die sere word uitgesny en dit raak nie gesond nie. Dit voel net vir my die dokters vererger dit, dat dit al seerder raak." (Hester)

Hester, as most mothers with HIV/AIDS, not only had her own health to be concerned about, but also cared for an HIV-infected daughter and partner, who both had AIDS-

related illness symptoms. The illness cycle she had to deal with on a daily basis caused her to feel extremely hopeless and worn out:

"And then it breaks me down again, because when she (her daughter with HIV) just starts getting a tiny cold then she's weak weak weak, then then it seems to me yes Lord now what, it's now my last. Because when she starts, then I also just start or if the dad starts then the child starts as well…I don't know how it is, what it is that it's like that, Elsa man." (Hester)

"En dan breek dit my weer af, want net as sy (haar dogter met HIV) beginne 'n verkouetjie kry dan is sy pap pap pap, dan dan lyk dit vir my ja Here nou wat, is nou my laaste. Want dan as sy beginne dan begin ek ook sommer of as die pa beginne dan beginne die kind ook… Ek weet nie hoe is dit, wat is dit dat dit so is nie Elsa man." (Hester)

"And I said to myself, my child is already deteriorating, I'm deteriorating, the dad is deteriorating… his head was covered with sores Elsa covered with sores and the child's chest doesn't want to get right and the child's breathing seems as if it is just going to collapse every five minutes." (Hester)

"En ek het by myself gesê, my kind gaan al agteruit, ek gaan agteruit, die pa gaan agteruit… sy kop was vol sere Elsa vol sere en die kind se bors wil nie reg nie en die kind se asemhaling lyk of dit net toe gaan toeval elke vyf minute." (Hester)

Schoepf (cited in Strebel, 1995) stated that women often must add the load of caring for infected family members to their already extensive duties in the domestic and formal employment spheres. Bunting (2001) found that "women caring for their sisters, brothers and children who were HIV-infected faced a burden of grief and discouragement" (p.145). According to her this burden was more devastating when the caregiving woman was infected herself.

Many other participants were also concerned about their partner's or child/children's illness condition. Joeyce narrated her concerns for her partner with AIDS as follows:

"…because then he (her boyfriend) just constantly kept on getting the boils down below, and constantly he's now had them more than six times…That's why I'm in such a hurry to go to the clinic, he doesn't want to, he definitely refuses… And he's getting thinner and thinner, he's getting thinner and thinner. He hardly has any buttocks left. This morning he was sitting on the bed then he wanted to put on his shoes. I watched him, when he couldn't do it, he got out of breath. " (Joeyce)

"…want toe kry hy (haar mansvriend) net aanmekaar die boils onder, en aanmekaar hy het nou al meer as ses maal al gehad… Dis daarom wat ek so haastig maak om kliniek toe te gaan, hy wil nie, hy weier beslis… En hy raak al hoe maerder, hy raak al hoe maerder. Hy is skaars amper stêre meer. Vanoggend sit hy op

die kooi nou wil hy sy skoene aan vat. Ek hou hom dop, as hy nou nie kan nie dan raak hy kort asem." (Joeyce)

"...and I talk to him, why don't you go to the doctor, but he doesn't take me seriously. He doesn't understand when I talk to him...So I try my best to help him, but he doesn't want to be helped and that hurts me." (Joeyce)

"...ek praat met hom hoekom gaan jy nie dokter toe nie, maar hy neem nie vir my kop toe nie. Hy verstaan nie as ek praat met hom nie... So ek probeer my bes om hom te help, maar hy wil nie gehelp wees nie en dit maak my seer." (Joeyce)

Joeyce stated further that because of her infecting her partner with HIV, she felt obliged to care for him, although she had to cope with illness symptoms of her own:

"I know what I've done to him. Now in the end to leave him then he's going to, he will quickly go downhill without me. Without me he wouldn't be able to cope, who's going to look after him?" (Joeyce)

"Ek weet wat ek aan hom gedoen het. Nou op die ou end vir hom te los dan gaan hy, hy sal gou in die afdraande gaan sonder my. Sonder my sal hy nie kan nie, wie gaan na hom kyk?" (Joeyce)

The participants' experiences seem to be shaped by an understanding that a "good" woman and mother is self-sacrificing, one who puts others first even if in pain or distress herself. It may also suggest that an ideal caregiver is a healthy woman, a woman not infected with an illness such as HIV/AIDS. In the literature it is stated that HIV-infected women in general experience distress and worries concerning HIV-infected family members. In the study conducted by Sarna et al. (1999) the women's concerns about the progression of HIV were ever-present, and included anxiety and worries about the family in general as well as other family members with HIV/AIDS. Broun (1999) emphasised that HIV-infected women carry double or even triple burdens, because of their responsibility to care for healthy and sick family members, which usually becomes the first priority for these women. It is difficult for a woman to give up the role as primary caretaker, even though she herself may be sick (Broun, 1999). Broun (1999) referred to women patients who would cook dinner for their families even though they had neither the strength nor energy to eat. These experiences seem to be informed by an understanding that a woman is someone who cannot let go of her care-taking responsibilities even if she is in serious need of care herself.

Elna, Nossie and Hester, like most other participants with HIV-positive children, were extremely distressed about their children's illness condition and the pain and suffering caused by it:

"That's my torment, I think of it oh every day, what am I going to do the day that I have to lose my child. Suddenly, suddenly have to lose her, because she has the chest, she has the ears and uh I can't say anymore, because she's also now breaking out in such pimples." (Elna)

"Dis my kwelling, ek dink ai elke dag daaraan, wat gaan ek die dag doen as ek my kind moet verloor. Skielik, skielik moet verloor, want sy het die borsie sy het die oortjies en uh ek kan nie nog sê nie, want sy slaan nou ook sulke puisies uit." (Elna)

"But I was just in tears it was just I just cried. The tears just ran of their own accord and and I sat there next to my child and I just kept praying to the Lord. I asked the Lord I asked the Lord does the child now have (HIV), does she have to suffer like this." (Nossie)

"Maar ek was net in trane dit was net ek het net gehuil. Die trane het net vanself geloop en ek het gesit daar by my kind en ek het net biddend gebly by die Here. Ek het vir die Here ek het vir die Here gevra het die kind dan nou, moet sy so ly." (Nossie)

"To me it just feels my little girl feels to me very important in my life. I do everything that's within my power for her. I do I struggle for everything for her, I make sure that she's clean…The chest, to me it's just the chest, she can only cry for a short while… then she starts heee (subject makes a hoarse sound). And then those vocal cords of hers are gone, Elsa…" (Hester)

"Vir my voel dit net my dogtertjie voel vir my baie belangrik in my lewe. Ek doen alles in my vermoë vir haar. Ek doen ek sukkel vir alles vir haar, ek sorg dat sy skoon is… Die bors, dis net vir my die bors, sy kan net 'n tydjie gehuil… dan begin sy heee (subjek maak hees geluid). En dan is daai stembande weg van haar Elsa…" (Hester)

It is clear from the above citations that the participants in the present study had multiple responsibilities and daily stressors, because of caring for ill children and/or partners. In the literature it is emphasised that because of the demands placed on HIV-infected women, as mothers, spouses, and caregivers, they tend to view their own healthcare and needs as less important than the needs of other family members, especially their children. Rose (cited in Rose & Clark-Alexander, 1996) found in her study of HIV-infected women that concerns of caring for children were much higher than caring for their personal health. A study conducted by Rose et al. in 1996 (cited in Sarna et al., 1999) found that the

psychological domain of quality of life was the most disrupted for HIV-infected women with children. It can be argued, then, that the progression of the illness in these women, as in the case of the women in the present study, would most probably be quicker than in women just caring for themselves or those that receive sufficient care from others.

5.3.8 Concerns regarding infecting others

Some of the participants in the present study were anxious that they would be responsible for infecting other people with the virus:

"Say I want to go and visit people and um I'm making food, now I cut my hand and and I haven't told them I'm HIV+, you understand Elsa … And perhaps they eat the salad I've made and I don't say anything to them. My finger bleeds and they help me, but that blood there perhaps and somebody may have an open cut. Now they get it (HIV) or so …" (Nossie)

"Sê ek wil by mense gaan kuier nê en um ek is besig om kos te maak nou sny ek my hand raak en en ek het nie vir hulle gesê ek is HIV+ nie, verstaan Elsa… En hulle eet miskien die slaai wat ek gemaak het en ek sê niks vir hulle nie. My vinger bloei en hulle help vir my, maar daai bloed miskien nou daar en iemand het dalk 'n stukkende plekkie. Nou kry hulle dit (HIV) of so…" (Nossie)

Hester feared that she or her HIV-positive daughter could infect others through blood contact:

"I don't want to infect other people with the illness as well. I want to with my kids…they mustn't make contact with blood things, blood clothes or something or if someone has hurt her and her finger bleeds or they bumped their heads against each other. The one's nose is bleeding and the other one's nose is bleeding, then it just feels to me that I'm so scared… I'm scared my child could infect the other children through the blood touching. Then I take her away and I clean her up… that she is just apart away from the others." (Hester)

"Ek wil nie ander mense aansteek ook met die siekte nie. Ek wil met my kinders… hulle moet nie kontak maak met bloed goed, bloed klere of iets of as iemand vir haar seergemaak het en haar vingertjie bloei of hulle het gekap teen mekaar se koppe. Die een se neus bloei en die ander een se neus bloei, dan voel dit net vir my ek is so bang… Ek is bang my kind kan die ander kinders aansteek deur die bloed aanmekaar te raak. Dan vat ek vir haar weg en ek maak vir haar skoon… dat sy nou net eenkant weg van mekaar af is." (Hester)

Broun (1999) found that the mothers who wanted to keep their own and their children's HIV-status a secret, felt obliged to warn their children not to let anyone come into contact with their blood, should they hurt themselves. Protecting their children as well as those around them was therefore a double burden for these mothers.

Rosy told her employer about her illness, because of fear of infecting the family members she worked for:

"And there was a woman here who also worked in Mitchell's Plain, a char, and then I just told her about my... HIV and all that. I see it like this, perhaps I hurt myself and then touching them with the blood and she understood me." (Rosy)

"En toe was hier 'n vrou wat ook gewerk het in Mitchell's Plain, 'n char, en toe vertel ek sommer vir haar ook nou van my... HIV en daai. Ek vat dit so miskien maak ek my nou seer en dan aanraking saam met die bloed met hulle en sy het my verstaan." (Rosy)

Hester also feared infecting her healthy child:

"Because we're scared we can (infect) our little boy who doesn't have it... if I have a wound on me... I'm so very scared. I cover it, because I don't want to contaminate him with the virus. And even if he has a sore, I bring him to the clinic so that the sisters can just look at it because I feel so scared I don't want to others with the same pain which I have gone through and still now." (Hester)

"Want ons is bang ons kan ons seuntjie wat dit nou nie het nie... as ek 'n seerplek op my het... ek is skoon so bang. Ek maak dit toe, want ek wil nie vir hom vir hom besmet met die virus nie. En even as hy 'n seer het, ek bring vir hom kliniek toe dat die susters net kan kyk daarna, want ek voel so bang ek wil nie ander met dieselfde pynigheid wat ek deurgegaan het en nou nog." (Hester)

The above citations show that most of the participants were aware of the ways in which HIV can be transmitted and they were extremely cautious not to infect other people with whom they came into contact. It seems that these participants did not want to inflict the pain and distress of having HIV/AIDS on any other person.

5.3.9 Summary

The participants reported a wide range of physical symptoms, such as weight loss, fatigue, and pain, which influenced their daily functioning and overall quality of life. The

experience of weight loss as the most visible symptom of being HIV-infected was very prominent in the narrations of the participants. The participants were particularly anxious that others would guess their diagnosis because in their community, as in most other disadvantaged communities, weight loss is one of the most commonly known visible signs of having HIV/AIDS. Also inherent to the participants' distress about losing weight seems to be a notion of womanhood, that a woman should not be too thin. This might also constitute part of a gendered discourse of what it means to be a "good" woman. The effect of weight loss on the participants' experiences of their own womanhood is discussed in more detail under section 5.4.1.2, Loss of woman- and motherhood, of this chapter.

The high levels of fatigue and pain experienced by the participants in this study had a negative effect on their daily functioning, their productivity and performance at home and at the workplace. This again highlights a dominant discourse of women as primary caregivers, which suggests that women are expected to care for others regardless of their own situation. This might also show part of a gendered disourse of what it means to be a "good" woman; a woman that is able at all times to fulfil her duties in the home and in the workplace.

For many participants, not only the pain and discomfort of their illness symptoms, but also the management and treatment of these symptoms, caused them physical and emotional distress. Further distress and anxiety were experienced when a participant had to care for an HIV-infected family member, such as a partner and/or child, as well. According to Dodd et al. (cited in Hudson et al., 2003), physical symptoms can be distressful and frustrating for patients and caregivers because they often are not acquainted with management approaches that would be appropriate, and because symptoms can be erratic owing to their dynamic and varying nature. These findings suggest a discourse of HIV/AIDS as an illness of severe physical suffering. Concomitant with the discourses of silence, separation, and loss, it is argued, then, that a woman with HIV/AIDS will suffer alone without adequate care and support. Consequently, medical treatment, self-care and support are of great importance for women with HIV/AIDS in order to treat symptoms and prolong physical well-being.

According to Sowell et al. (1999), like other long-term and chronic illnesses, HIV/AIDS is an extremely complex illness process that affects all aspects of an individual's life. Although the most noticeable effects of the illness are physical ones, HIV/AIDS is also emotionally, socially, and spiritually distressing. Sowell et al. (1999) explained that during the various stages of the illness, issues relating to psychological, social, and spiritual needs are apparent, and during periods when symptoms are not present or manageable, these issues may actually be of greater importance than the physical health issues associated with the illness. Thus, the participants' experience of HIV/AIDS as an illness condition that has a detrimental effect on all areas of their well-being are shared by women in other communities.

In the participants' accounts of their illness experience, two dominant discourses can be highlighted. The first discourse is a discourse of HIV/AIDS, within which the illness is constructed as an incurable and deadly illness; of HIV/AIDS as a shameful illness that someone should be blamed for; and of HIV/AIDS as being associated with silence, separation, loss, and suffering. The second relevant discourse is a discourse of mothering, what it means to be a "good" woman/mother and caregiver. The discourse of HIV/AIDS as an illness and the discourse of a "good" woman/mother and caregiver seem to be incompatible, because a "good" women and caregiver is constructed as someone who is connected, physically strong, healthy and productive, someone who should primarily take care of her children and family, and not be separated from them, or neglect or abandon them through illness or death.

The experiences of the participants show that their physical illness symptoms and those of their infected family members, as well as the management of these symptoms, most definitely strained their daily functioning and negatively affected their psychosocial well-being and quality of life. Rose and Clark-Alexander (1996) stated that clinical characteristics of HIV/AIDS have been directly related to overall well-being and a decline in quality of life. Thus, HIV/AIDS is constructed as a distressing, incurable, and stigmatised illness that causes a woman to experience various physical and psychosocial losses. These

losses can influence and change a woman's day-to-day existence. In the next section the focus will be on the psychosocial losses experienced by the participants in the present study.

5.4 Losses and effect on daily living

The participants in the present study experienced many psychosocial losses after being diagnosed with HIV/AIDS, which caused them immense emotional distress and pain in their daily lives. These losses can be ascribed to the actual illness experience, as well as to the ways in which the illness was constructed within the community (an illness associated with stigma, rejection, and shame). Hester narrated her loss of personhood and of self in a very descriptive way. She articulated that she felt completely empty and deserted, as if everything and everyone that were important to her had been taken away from her, and she would never retrieve it:

"It (HIV/AIDS) makes me feel different Elsa, I feel then it feels to me again like someone who hasn't, doesn't have people around him or parents don't exist in my case... Someone hurt me or someone took my things and now he's gone and now I'll never get them back again..." (Hester)

"Dit (HIV/VIGS) laat vir my anderster voel Elsa, ek voel dan voel dit weer vir my soos een wat nie, wat nie mense rondom hom het of ouers bestaan nie by my nie... Iemand het vir my seergemaak of iemand het my goete gevat en nou is hy weg en nou gaan ek dit nooit weer kry nie..." (Hester)

For Joeyce, being 26 years of age, it was a terrible shock to contemplate that she had been infected with HIV at such a young age when there were so many years still ahead of her. For her it was the loss of life:

"I was greatly, terribly shocked to think I'm still young in life and now to be saddled with the virus." (Joeyce)

"Ek was groot vreeslik geskok gewees om te dink ek is nog jonk in die lewe en nou opgeskeep te sit met die virus" (Joeyce)

All the other participants, like Hester and Joeyce, experienced great losses that caused them severe emotional distress. The next section will commence by focusing on the "loss of self" and then on "the loss of life" experienced by these women.

5.4.1 'Loss of self'

5.4.1.1 Loss of self-worth / self-confidence

Many of the participants narrated feelings of worthlessness that had a negative effect on their sense of self, self-image, and self-confidence. Certain participants narrated experiencing a loss of self:

"... I I felt so that I am nothing I am nobody and I am um..." (Sylvie)

"...ek ek so gevoel ek is niks nie ek is niemand nie en ek is um..." (Sylvie)

"Now when I heard I now have this sickness I felt so small... Because I feel there are sometimes things that I don't that I no longer want to do, like this sickness now I'm too scared to do something. Does Elsa understand?" (Nossie)

"Toe ek nou hoor ek het nou hierdie siek toe voel ek so klein... Want ek voel daar is somtyds dinge wat ek nie wat ek nie meer wil doen nie, soos hierdie siek nou ek is te bang om iets te doen. Verstaan Elsa?" (Nossie)

"I'm no longer the same person that I used to be..." (Sonja)

"Ek is nie meer dieselfde mens soos ek gewees het nie..." (Sonja)

Bertha felt very negative about herself:

"But I feel so bad about myself, I feel very bad about myself... It now depends, how bad I feel ...just that I feel so bad..." (Bertha)

"Maar ek voel so sleg oor myself, ek voel baie sleg oor myself... Dit hang nou af, soos wat ek nou so sleg voel... net dat ek so sleg voel..." (Bertha)

Hester narrated how the illness caused her the loss of self-confidence:

"It feels to me that the HIV virus has taken something away from me...I don't know if it's my self-confidence, but it has taken something away from me... The sickness doesn't leave me in peace." (Hester)

"Dit voel vir my die HIV virus het iets weg van my af gevat... Ek weet nou nie of dit my selfvertroue is nie, maar dit het iets weg van my af gevat... Die siek laat my nie met rus nie." (Hester)

Participants in the study conducted by Boyle, Hodnicki and Ferrell (1999) also struggled to deal with the negative public perception about HIV/AIDS and to maintain a sense of positive self-worth in the face of stigma, while they were caring for their children and other family members with HIV/AIDS. Leenerts and Magilvy (2000) declared that the sense of self in low-income HIV-positive women is portrayed in the literature as fragile and socially constructed in ways that make them vulnerable to poor physical and mental health. Nieumeyer (2002) found in her study of HIV-infected Xhosa women that living with AIDS can be a very disfiguring process and that there is a loss of self-esteem.

5.4.1.2 Loss of woman- and motherhood

Some of the participants in the present study felt that they had been scarred by the physical symptoms of the illness and this had a detrimental effect on their experience of their womanhood:

"I'm actually very ashamed to walk outside with such a face, because um the ear has now healed nicely, the nose as well. But now it's the eyes again the eye and the lips and then the the boils I get." (Elna)

"Ek is eintlik baie skaam om buitekant te loop met so gesig, want um die oor het nou baie mooi gesond geraak, die neus ook. Maar nou is dit nou weer die oë die oog en die lippe en dan die die swere wat ek kry." (Elna)

Hester narrated that her physical symptoms made her feel different from other young women, she felt almost like an outcast, and this caused her extreme emotional pain and aloneness:

"Then it's just me and the sickness that I think of or the pimples, when are they going to get healed. Why why I can't also be like the other young girls, see how pretty they're looking today... It makes me feel it just makes me feel very bad, it doesn't make me feel like a woman. It just feels to me as if I'm the only woman on earth who has to endure so much pain Elsa, I'm the only woman carrying boils in my face." (Hester)

"Dan is dit nou net ek en die siek wat ek aan dink of die puisies, wanneer gaan dit gesond raak. Hoekom hoekom kan ek dan nie ook soos die ander jong meisies is nie, kyk hoe mooi lyk hulle nou vandag... Dit laat my voel dit laat my net baie sleg voel, dit laat my nie voel na 'n vrou nie. Dit voel net vir my ek is die enigste vrou op aarde wat so baie pyn deur moet gaan Elsa, ek is die enigste vrou wat swere in my gesig dra." (Hester)

Broun (1999) stated that women feel unattractive because of constant skin problems, wasting, loss of hair, thrush or any number of other noticeable signs of AIDS. Hackl et al. (1997) reported that women often feared a more rapid disease progression and no longer viewed themselves as attractive or desirable. According to Broun (1999), the loss of self-esteem and feelings of hopelessness engendered by the biological progression of the illness can even be more destructive and damaging for a woman than the physical symptoms. Leenerts and Magilvy (2000) emphasised that the women participants in their study who experienced a loss of self failed to engage in proactive self-care or coping strategies.

The majority of the participants in the present study expressed their concern about losing weight. For Sylvie and Joeyce, their own body image changed after they had been diagnosed with HIV. They narrated that losing weight was like losing a part of themselves:

"...but I'm just scared because look I also when I when I heard that I have AIDS, I also every day on my weight. I just felt uh I'm no longer I don't have the physique I used to have. And whether it's time that's making me waste away and many times I eat, but I never feel that I'm putting weight on me." (Sylvie)

"...maar ek is net bang want kyk ek het ook toe ek dit toe ek gehoor het dat ek VIGS het, het ek ook elke dag op my gewig. Ek het net gevoel uh ek is nie meer ek het nie meer die liggaamsbou wat ek gehad het nie. En of dit nou tyd is wat my so uitteer en baie kere dan eet ek, maar ek voel nooit dat ek gewig aan my aansit nie." (Sylvie)

"I just have to, the only problem I have with the thingummies is just that sometimes I can't get food into me... I didn't use to be so thin. My arms are now so thin I don't even want to wear a short-sleeve thing anymore...There is, how can I say it, seems that there is a whole part of my body that's no longer with me." (Joeyce)

"Ek moet net, al probleem wat ek het met die dingese is net dat ek partykeer nie kan kos in kry nie... Ek was nie so skraal nie. My armpies is dan nou so dun ek wil nie eers meer 'n kortmou ding dra nie... Daar is, hoe kan ek nou amper sê, lyk dit daar is 'n hele part van my liggaam is nie meer met my nie." (Joeyce)

From the above citations it is clear that in these communities the construction of womanhood has to do with a woman's physical appearance, her weight, a healthy skin, dressing-up and looking attractive. Thus, it is understandable that the participants experienced a loss of their womanhood.

Because of the illness, Hester was not motivated to care for herself or her children as she did before. She narrated that the illness changed her personality, because she loved dressing-up and going out with her kids, but since the HIV diagnosis she had become withdrawn:

"My life has changed a lot, because I used to love looking after myself and I usually went out with my children… Not now with the AIDS, the TB the TB had me so seriously ill Elsa I didn't want to pull together my my personality or myself for me or my children." (Hester)

"My lewe het baie verander, want ek was lief om na myself te kyk en ek het gewoonlik met my kinders uitgegaan… Nie nou met die VIGS nie, die TB die TB het my mos so ernstig siek gehad Elsa ek wil nie vir my my persoonlikheid of myself reggeruk of my kinders nie." (Hester)

In the literature it is emphasised that visible symptoms like weight loss can isolate women with HIV/AIDS and lead to further emotional distress such as loneliness and depression (Withell, 2000).

Some participants experienced the loss of motherhood. Sylvie, the eldest participant and the mother of the most children, revealed feelings of loss for not living with her children and being able to give them the motherly care they needed:

"…what will become of me what will become of my children…I just don't know what to do, but I feel very hurt because they (her children) are so far away. It doesn't feel to me as if they, they don't get love there where they are staying. Oh, it might perhaps be a sister perhaps who would care a little, but it's just not there's just not a mother." (Sylvie)

"…wat gaan van my word wat gaan van my kinders word… Ek weet net nie wat om te doen nie, maar ek voel baie seer omdat hulle (haar kinders) so ver weg is. Dit voel nie vir my of hulle, hulle kry nie liefde nie daar waar hulle bly nie. Ag dit sal nou 'n suster wees miskien wat sal omgee bietjie, maar dis net nie daar's net nie 'n ma nie." (Sylvie)

Sonja experienced deep sadness for not being in the position to care for her newborn baby, who had been placed in a care centre for HIV-infected children by Welfare:

"…I now feel sad about things that happened towards because of me and now my child (her baby) is, to think that he now also has that illness…. I want him to come back (subject cries)…Just my baby he must come home…" (Sonja)

"...ek voel nou hartseer oor dinge wat nou gebeur het teenoor nou oor my en nou is my kind (haar baba) om te dink dat hy ook nou daai siekte het... Ek wil hê hy moet terug kom (subjek huil)... Net my baby hy moet huis toe kom..." (Sonja)

The participants' experiences seem to be informed by an understanding that a mother is the primary caretaker of children, someone who is responsible for children's needs on all levels, physical as well as emotional. The findings of the present research as well as numerous other studies show that the disabling aspects of HIV/AIDS almost certainly affect women's competence to be actively involved in their children's physical care and emotional development. Broun (1999) explained that even if the family's relationship with the community and extended family is one of openness and acceptance, a mother will battle with her own internal feelings of loss, anxiety, depression and sadness about her inability to be a good mother to her children and family. These feelings of inadequacy are closely related to feelings of hopelessness and helplessness that, in turn, cause mothers to question the meaning of their lives.

Just one participant in the present study, Elna, stated that she desperately wanted another child, even though her only child was HIV-positive. Opportunistic infections most probably deprived her of the possibility of falling pregnant:

"I'm ready for another baby, having another baby. I want to very much, much, much, but...Yes, I'll take the chance...I don't know I don't know there's also probably something wrong with me because I use nothing Elsa and I can't fall pregnant. So there's something seriously wrong with me, but I think it's the warts I'm getting. Yes I will I will go again to go and listen, let them do a test if I can ever get pregnant or what." (Elna)

"Ek is reg vir nog 'n babatjie, nog 'n babatjie hê. Ek wil graag, graag, graag, maar... Ja, ek sal die kans vat... Ek weet nie ek weet nie daar is iets fout ook seker met my, want ek gebruik niks nie Elsa en ek kan nie swanger raak nie. So daar is groot fout by my, maar ek dink dit is die vratte wat ek so kry. Ja ek sal ek sal weer maar gaan om te gaan luister, laat hulle 'n toets maar doen of ek ooit kan swanger raak of wat." (Elna)

Overall (1991) stated that many healthcare policies advocate that HIV-infected women refrain from falling pregnant. Therefore, the social construction of HIV/AIDS may have powerful effects on women's self-image as mothers, for it threatens the standard view of women as reproducers. Overall (1991) stated the following:

> Abstaining from sex, which amounts to abstaining from having babies, is an unlikely solution for a woman who may find children her sole source of love and self-worth, perhaps her sole hold on a man upon whom she depends for money. (p.30)

Overall (1991) pointed out that many HIV-infected women who are disadvantaged and economically dependent on their male partner will take the risk of falling pregnant even though their chances of having an infected infant are high.

On the contrary, certain women fear infecting their unborn child with HIV and consequently refrain from falling pregnant. In the present study Nossie decided against a second pregnancy for fear of having another HIV-positive baby:

"Then I decided from that point, my child has to suffer so much. My only one must now endure so many things, I won't go and fetch another one. Then I said to the doctor I feel um my child also has the sickness and I have the sickness and um now I'm going to take a chance again." (Nossie)

"Toe het ek van daar af besluit, my kind moet dan so ly. My enigste een moet nou so deur baie dinge gaan, ek sal nou nie weer enetjie gaan haal nie. Toe sê ek vir dokter ek voel um my kind het ook die siek en ek het nou die siek en um nou gaan ek weer 'n kans vat." (Nossie)

Hackl et al. (1997) reported that women often felt that their reproductive rights were socially disapproved of. Schable et al. (cited in Murphy et al., 2002) and Sowell et al. (1999) confirmed that the majority of women diagnosed with HIV infection are women of child-bearing age (16 to 44 years of age). According to Sowell et al. (1999), these women must make a series of complex decisions regarding contraception, pregnancy and abortion. Levine (cited in Lorber, 1997) stated that many women suffering from chronic illnesses, and even some who are dying, choose to become pregnant despite the health risk involved. Although the potential for perinatal transmission of HIV to a baby may be expected to discourage HIV-infected women from becoming pregnant, existing research suggested that HIV-status is not the main influence in reproductive decision-making for many women (Sowell et al., 1999). According to Cohan and Atwood (1994), women, HIV-infected or not, derive self- as well as social esteem from having children and caring for them. Thus, given a discourse within which HIV-infected women are constructed as vectors of HIV transmission, it is understandable that women feel judged and deprived of their basic rights as women and mothers.

The narrations of the participants in the present study show that in their communities womanhood is primarily constructed as being involved in reproduction and being caregivers. Heath and Rodway (1999) pointed out that special needs of HIV-infected women and mothers are the psychosocial needs related to their reproductive capabilities and to their role as caregivers in the home. In the present study, the majority of the participants did not express the need for having more children. They in fact expressed the need for support with caring for their existing children, particularly when they felt physically ill or emotionally drained.

5.4.2 "Loss of life" (Loss of a way of life)

5.4.2.1 Loss of intimacy and married and family life

Being HIV-infected caused many of the participants in the present study to mourn the loss of a satisfying intimate relationship, as well the possibility of marrying and having a family. Elna disclosed her need for having a husband and family in the future as follows:

"But my desire I would like to be a family on my own, married I would like to marry one day and um have more children, but I want a husband as well." (Elna)

"Maar my begeerte ek wil graag 'n familie op my eie is, getroud ek wil graag eendag trou en um nog kinders hê, maar ek wil 'n man ook hê." (Elna)

For Joeyce, there was little hope of getting married and making a home with her partner because he was seriously ill with AIDS:

"Before he started getting so thin…then he said if he could now get a job, then we get a nice place. Then he said to me then he and I can get married at the court without further ado. But I don't believe this will happen, there probably won't be any time for that now. " (Joeyce)

"Voordat hy nog so maer beginne raak het… toe sê hy as hy nou 'n werk kan kry, dan kry ons 'n lekker plek. Toe het hy vir my gesê dan kan ek en hy sommer by die hof trou. Maar ek glo nie dit sal gebeur nie, daar sal seker nie nou nog tyd wees daarvoor nie." (Joeyce)

For Elna, the illness caused the break-up of an intimate and caring relationship:

"Look and now I'm not getting love from my parents, much less from H (her boyfriend). He has also now told.... we are rather friends, there won't be anything like a relationship between us as girlfriend and boyfriend again. " (Elna)

"Kyk en nou ek kry nie liefde van my ma-hulle af nie, nog minder van H (haar mansvriend) af. Hy het ook nou vir... gesê ons is eerder vriende, daar gaan nie weer iets soos 'n verhouding is tussen ons as meisie en kêrel nie." (Elna)

Two participants, Joeyce and Sylvie, blamed their previous partners who had infected them with HIV for depriving them of life and many dreams which they had for themselves and their children:

"I'm glad that he's dead, because he (former boyfriend) is a rubbish to have done that. And I'm now only 26 years old and he came and shortened my life. I've had so many plans for my life... and he shattered all of it. I still thought my boyfriend and I would get married one of these days, but it's never going to happen." (Joeyce)

"Ek is nou bly dat hy dood is, want hy (vorige mansvriend) is 'n gemors om dit te gedoen het. En ek is nou eers 26 jaar oud en hy kom verkort nou my lewe. Ek het so baie planne gehad vir die lewe... en hy het dit als opgebreek. Ek het nog gedink ek en my kêrel gaan nog een van die dae trou, maar dit sal nooit nie gebeur nie." (Joeyce)

"...I feel I he (her husband) deserved it, but it wasn't necessary why do I now have to deserve it and and why and what about my children...I why must I suffer under it and and I can't continue with my life. I mean if I didn't have it, it would be much easier for me. Then it would be nothing... And I've also told him, I could already have been married today and uh could have had a house and had my children with me. I say this you haven't even given me, all you brought me was misery." (Sylvie)

"...ek voel ek hy (haar man) het dit verdien, maar dit was nie nodig hoekom moet ek dit nou verdien en en hoekom en wat van my kinders... En hoekom moet ek daaronder ly en en ek kan nie met my lewe aangaan nie. Ek meen as ek nie dit gehad het nie, was dit vir my baie makliker. Dan was dit niks... En het ook al vir hom gesê, ek kan vandag al getroud gewees het en uh 'n huis gehad het en my kinders by my gehad het. Ek sê dit het jy nie eers vir my gegee nie al wat jy my gebring het was ellende." (Sylvie)

Sylvie's husband told her that she would be a man's death sentence should she have intercourse with a man. On the other hand, Sylvie felt that she carried a death sentence because of her husband infecting her with HIV, which meant that she was deprived of many opportunities in life:

"...I also told him he had said it's a man's death sentence if he gets involved with me and so. Then I said but it's you, you passed the death sentence on me..." (Sylvie)

"...ek het vir hom ook gesê hy sê dit is 'n man se dood vonnis as hy met my deurmekaar is en so. Toe sê ek maar dis jy jy het die dood vonnis oor my uitgespreek..." (Sylvie)

Sylvie also expressed that loss of life meant that she would never be able to have an intimate or sexual relationship in her life again, because of being HIV-infected:

"And that hurts me most of all, because I uh I mean when I've met a man and and we can't really have a relationship... And perhaps I also feel good towards the man, but uh it's of no use to to continue with a relationship." (Sylvie)

"En dit maak my die meestal seer, want ek uh ek meen as ek 'n man ontmoet het en en ons kan tog nie 'n verhouding hê nie... En miskien voel ek ook goed teenoor die man, maar uh dis niks werd om om met 'n verhouding aan te gaan nie." (Sylvie)

"Yes many times I miss like a relationship, but I... I suppose I break myself down and um I have had um a male friend that I felt very seriously about. And that I felt if we had to um start a real relationship it could be harmful... it's just not going to work... And many times then uh then I feel I I'm now totally empty..." (Sylvie)

"Ja baie kere mis ek soos 'n verhouding, maar ek... breek maar my seker self af en um ek het al um 'n mans vriend gehad teenoor wie ek baie ernstig gevoel het. En dat ek gevoel het maar as ons moet um 'n regtige verhouding aanknoop dan kan dit skadelik wees... dit gaan dit gaan net nie werk nie... En baie kere dan uh dan voel ek ek is nou is ek heeltemal leeg..." (Sylvie)

The above citations of the participants show that the illness deprived them of enjoying a close family life. Given the constructions of womanhood and motherhood in their communities, the illness also deprived them of their roles of being the "good" woman and mother that were expected of them and most likely what they themselves strove to be. According to Lesch (2000), the future perspective of women from lower socio-economic strata, who in Western countries frequently are women of colour, focus on traditional expectations of marriage and children. She stated further that these women are therefore also likely to construct their sexuality within the parameters of marriage and children.

Given the participants' construction of a woman as someone with sexual desires and sexual needs, it is comprehensible that because of their illness they were deprived of a satisfactory sex life. The majority of the participants complained that their intimate relationships with their partners were unfulfilling. Rosy explained that her feelings for her

husband on a sexual/intimate and emotional level changed completely after she had been diagnosed with the illness:

"It's my husband… he has now already infected me and now I'm just continuing with him…I feel um now when he (her husband) has sex with me, I'm not like I used to feel with him…It has changed completely…Not like husband and wife should be… no love and no uh strength in me for him…" (Rosy)

"Dit is my man… hy het my nou klaar besmet en ek gaan nou maar voort met hom… Ek voel um nou as hy (haar man) met my seks het, ek is nie soos ek gewoonlik gevoel het met hom nie… Dit het heeltemal verander… Soos man en vrou nou moet is nie… niks liefde en niks uh krag in my vir hom nie…" (Rosy)

Findings from the present study correlate with research observations made by Sarna et al. (1999), namely that women with HIV/AIDS experienced difficulties with communicating with their partners and altered sexual function.

Ann, like many participants, verbalised that her desire for an intimate and sexual relationship with her partner decreased. Her experience was similar to that of other participants in the present study, who were blamed by their husbands/partners of infidelity because they declined to have sex with them:

"I hope for a good relationship in the two of us, because in bed we (she and her husband) sleep like brother and sister. Don't really do anything sexual with each other any longer…And he mustn't touch me. And then for no reason he says I've got another man, you're bad and you're this and he calls me names." (Ann)

"Ek hoop vir 'n goeie verhouding in ons twee, want in die bed slaap ons (sy en haar man) soos broer en suster. Worry nie eers met mekaar eintlik meer nie…. En hy moenie aan my vat nie. En dan sê hy sommer ek het 'n ander man, jy is sleg en jy is dit en hy skel my uit." (Ann)

According to Leclerc-Madlala (2000) and McDonnel and Gielen (2003) women's fear of potential abuse affects their willingness or ability to talk openly about sexual intercourse with their partners. Women's difficulty in negotiating safer sex, being HIV-infected or not, is thus mainly due to their lack of power in interpersonal relationships, and difficulty with talking openly to their partners, as well as being financially dependent on their partners. According to Broun (1999), many HIV-infected women practise unsafe sex with their infected partner for the above reasons. Broun (1999) warned that certain specific viruses (such as cytomegalovirus) could be passed to them, as could more virulent strains of HIV.

Hester rejected her partner's sexual advances because of her physical illness symptoms that caused her pain and discomfort. Hester was one of the participants with the most serious illness symptoms and she expected her partner to show more understanding for her condition:

"And as a result of the illness we have, he wants to sleep with me, the sores I have here between my buttocks. That I can, he can also get it on those places by sleeping with me." (Hester)

"En as gevolg en die siekte wat ons het, hy wil nou met my saam slaap, die sere wat ek hier tussen my boude het. Dit kan ek, hy kan dit ook op daai plekke kry deur saam met my te slap." (Hester)

"How long haven't I had the problem, the sores in my body in the lower part of my body, the sores under my armpits. It's been it's been more than a year that I've been sitting with the problem. And also when we have intercourse I and… we also can't have intercourse as usual Elsa…there are many times when he wants to have intercourse with me then I tell him, he knows for a fact that the doctors have also told him he makes me more ill." (Hester)

"Hoe lank het ek nou nie die al probleem nie, die sere in my liggaam in my onderliggaam, die sere onder my blaaie. Dit is al dit is nou al meer as 'n jaar wat ek met die probleem sit. En as ons omgang ook het ek en… ons kan nie soos gewoonlik omgang ook het nie Elsa… daar is baie kere as hy met my wil omgang dan sê ek vir hom, hy weet vir 'n feit dat die dokters ook vir hom gesê het dat hy maak vir my nog sieker." (Hester)

Lesch (2000) found in her study on sexuality and young Coloured women that the women did not perceive it as a right that their sexual discomfort or pleasure must be considered by a man. She stated that it is something that the man had the power to bestow or withhold. According to Cohan and Atwood (1994) a failure to acknowledge the "power differential" in many intimate relationships is a failure to consider the cultural, social and economic imperatives that shape women's lives.

Hester's husband also accused her of infidelity, even though he knew about her serious and painful physical symptoms:

"Why doesn't he give me a chance and wait and see until it heals…but then it seems to him then it feels to me Elsa he he could think I'm sleeping around or so. Then he also says to me, are you sleeping around. Then I say to him it's not that, he knows what the problem is… He knows for a fact what's wrong with me…" (Hester)

"Hoekom gee hy nie vir my 'n kans nie en wag en kyk tot dit gesond raak nie… maar dan lyk dit vir hom dan voel dit vir my Elsa hy hy kan dink ek slaap in die rondte of so. Dan sê hy ook vir my, slaap jy dan in die

rondte. Dan sê ek vir hom dit is nie dit nie hy weet dan wat die probleem is... Hy weet dan vir 'n feit wat ek makeer..." (Hester)

Various writers emphasised that gendered power relations are fundamental to the negotiation of safer sex and sexual practices (Lesch, 2000; Miles, 1995; Strebel, 1993). Holland, Richardson and Patton (cited in Miles, 1995) stated that women are in a subordinate position in relation to men; therefore in diverse social contexts it may be problematic or impossible for a woman to negotiate with a man regarding sexual matters. According to these writers various reasons connected to the power relations of gender inhibit women from suggesting the use of a condom or openly talking to their partners about their sexual priorities and needs. It can be argued, then, that several disempowering causes interacted with the participants in the present study in a very specific socio-economic context to engender sexually disempowered individuals.

The illness symptoms of Joeyce and her HIV-infected partner caused them not to have sexual intercourse any longer:

"My boyfriend, the one I have now. He says then, he gets tired too soon. He says it hurts him, because I'm almost, now how can I say, I just stay closed down below. And the day he wants to, how can I say, wants intercourse with me, then he has to have a difficult time with me. That's why I don't worry...We don't do it anymore, it's more than four months that we don't get amorous with each other...We just sleep next to each other but nothing more happens..." (Joeyce)

"My kêrel, die ene wat ek het. Hy sê dan, hy raak te gou moeg. Hy sê hy kry seer, want ek is amper hoe kan ek nou sê ek bly sommer so toe van onder. En as hy die dag wil, hoe kan ek sê wil omgang hê met my, dan moet hy sukkel met my. Dis daarom wat ek nie worry nie... Ons doen dit nie meer nie, is meer as vier maande wat ons nie worry met mekaar nie... Ons slaap net langs mekaar maar daar gebeur niks meer nie..." (Joeyce)

Broun (1999) found that as the illness progressed, patients began to experience multiple losses, inter alia a loss of previous sexual behaviour, physical changes, loss of important others from this illness, and loss of hope.

Bertha narrated that she was very cautious of men after her diagnosis and was not bothered to have a boyfriend again. For her it meant the loss of sexual relationships and staying abstinent forever:

"I'm not really worried about the guys and that, I don't worry any more. I have to look after myself well, I must beware of men and that kind of thing… I'm finished with the boyfriends….No sister, I don't worry any more, I must rather just stay like this until I die altogether…" (Bertha)

"Ek worry mos nou eintlik nie nou meer van die outjies en daai, ek worry nie meer nie. Ek moet vir my mooi oppas ek moet oppas vir die volk en daai… ek is klaar met die boyfriends… Nee suster ek worry nie meer nie, ek moet eider maar net so bly tot ek heeltemal gaan dood gaan…" (Bertha)

Brown et al. (cited in Morrow et al., 2001) reported the diagnosis of hypoactive sexual desire disorder in women with HIV. These authors hypothesised that this dysfunction may be a consequence of a number of different variables in a women's life, including the overall stress of adverse life events, negative self-image, fear of transmitting HIV to others, guilt, anger, and compliance with the expectations of medical authorities that HIV-positive women stay abstinent. In the present study the sexual desire of the participants was negatively affected by stressful life circumstances, relationship problems and conflict with partners, as well as illness symptoms. These changed sexualities most probably affected their experience of their womanhood in a negative way.

5.4.2.2 Loss of being productive

The high levels of fatigue experienced by the participants in the present study had a negative effect on their daily functioning and their productivity at home and in the workplace. Hester, the only participant diagnosed with both HIV and TB, experienced such extreme levels of fatigue that she struggled to perform her normal daily activities. She also narrated that her partner was dissatisfied with her for not doing her household duties:

"…the illness goes away and then it just comes then it goes again and it batters me it wears me down… But when he (her boyfriend) is also sick Elsa then he gets despondent, because he says I don't want to do anything. He does everything I do nothing, then I tell him it's not that, he must remember I have TB as well. The illness makes me so tired that if I've just fetched one jug of water, then it feels I shouldn't carry on doing the washing. Can't I ask someone to come and help me?" (Hester)

"...die siekte gaan weg en dan kom dit net dan gaan dit en dit takel dit my maak my gedaan... Maar as hy (haar mansvriend) ook siek is Elsa dan raak hy moedeloos, want hy sê ek wil ek wil niks doen nie. Hy doen alles ek doen niks nie, dan sê ek vir hom dit is nie dit nie, hy moet onthou ek het TB ook. Die siekte maak my so moeg ek kan net 'n een kan water kom haal het, dan voel dit ek moet nie meer wasgoed was nie. Kan ek nie iemand vra om my te kom help nie?" (Hester)

Joeyce also related how her physical condition hampered her performance in doing household tasks:

"And I wash her (her mother's) washing, baths baths full of washing I wash for her. Then sometimes I feel tired, pain here between my shoulder blades from all the rubbing." (Joeyce)

"En ek was haar (haar ma) wasgoed, baddens baddens wasgoed was ek vir haar. Dan voel ek partykeers moeg, pyn hier tussen my blaaie van al die vrywery." (Joeyce)

According to Heath and Rodway (1999), women's unique somatic experiences are often dismissed as psychological. The participants in Withell's study (2000) described a range of infections (such as tuberculosis, malaria, pneumonia) and other physical limitations that affected their ability to work. This often resulted in allegations of laziness or "being useless" (p.239).

Sylvie described how her illness state impacted on her performance at her formal work:

"And and I'm perhaps not as energetic as the others or I'm a bit slower than them (co-workers) and so on, but sometimes my body feels, my system really feels down...whether it's now age or whatever, but that I really feel I just want to go and lie down flat... not get up again..." (Sylvie)

"En en ek is miskien soos die anders so fluks nie of ek is bietjie stadiger as hulle (medewerkers) en so aan, maar my liggaam voel partykeer my, my gesteld voel regtig af... of dit nou die ouderdom is of wat ookal, maar dat ek regtig voel ek kan net gaan plat lê... nie weer op te staan nie..." (Sylvie)

Many participants conveyed that because of their ill health they did not have the energy or strength to look for work outside the home or be productive in the home:

"Then I make her porridge for the morning and I start with my washing or I wash and then I sit again for a little while when I get so tired...Now I say to her, oh dear, I don't know why I now have the sickness or so, (otherwise) I could have worked today..." (Rosy)

"*Dan maak ek nou haar pap vir die oggend en dan begin ek met my wasgoedjies of ek was of dan sit ek weer so 'n tydjie as ek so moeg raak... Nou sê ek vir haar ai ek weet nie hoekom het ek nou die siek of so nie, kan ek nou vandag gewerk het..." (Rosy)*

"But there are still many people going to the Boord (for work), but it's too far for me man… They walk far, into the town into Dalsig (a suburb)… it's far. I always used to walk like that when I had strength, but not any more." (Bertha)

"Maar daar gaan nog baie mense na die Boord (vir werk), maar dit is te vêr vir my man… Hulle loop vêr, daar in die dorp in Dalsig in… is vêr. Ek het altyd so geloop wat ek kragte gehad het… maar nie nou meer nie." (Bertha)

Sarna et al. (1999) stated that women with HIV/AIDS experience severe distress with role performance in and outside the home. As was the case with many of the participants in the present study, Broun (1999) also found that as the illness progresses patients begin to experience a loss of work and social functioning. According to Hudson et al. (2003), the extent to which fatigue affects women's daytime activities and functional status, such as their ability to be employed, care for their home and children and actively involve themselves in their communities, has not been a focus of research.

From the above citations of the participants it seems that in their communities a "good" woman is constructed as one that has the energy to earn money and to look after her children and home. Consequently, if she cannot live up to this notion of a "good" woman, collectively constructed in her community, she loses part of her womanhood. Therefore, it seems that the construction of AIDS as an illness that is incapacitating is incompatible with the construction of a "good" or successful woman.

5.4.2.3 Loss of a social life

The majority of the participants in the present study revealed a drastic change in life style and socialising patterns. Most of these participants did not have the need, desire, or energy to socialise with others that they had before their illness:

"I just don't feel like I used to be, I was a very lively person. I liked going out, went to dances, going out with my friends, went visiting and so on. I loved that very bitterly. I don't feel like going anywhere any more… I don't even feel like walking around, not at all." (Maggie)

"Ek voel net nie meer soos ek gewees het nie, ek was 'n springlewendige mens. Ek het gehou van uitgaan, danse toe geloop, saam met my vriende uitgaan, gat kuier en so aan. Ek was baie bitterlik lief vir dit

gewees. Ek is nie meer lus om iewers heen te gaan nie... Ek het nie eers lus om rond te loop nie, glad nie." (Maggie)

"When I heard heard it, it changed my life a lot. I don't want I don't want to go out, I don't want to be outside, I don't want people... they know they know I don't have the sickness but to me it seems everybody knows I have the sickness and I don't want to be noticed. I've sat in the house a lot, never went out, just sat... most of the time I'm just at home... then I'm alone." (Elna)
"Toe ek dit gehoor gehoor het, het dit my lewe baie verander. Ek wil nie seker ek wil nie uitgaan nie, ek wil nie buitekant is nie, ek wil nie mense... hulle weet hulle weet ek het nie die siek nie, maar vir my lyk dit almal weet ek het die siek en ek wil nie raakgesien wees nie. Ek het baie in die huis gesit, nooit uitgegaan nie net gesit... meeste van die tyd is ek maar net by die huis... dan is ek alleen." (Elna)

"The AIDS batters it exhausts me, it feels like I shouldn't have friends. I shouldn't communicate with other people, I should just be with my two children... I'm no longer like before going out of my own accord... no, I just sit at home weekends I just sit at home, I do my housework I sit. I no longer have that feeling like before like I had it before. Like with friends or so, I don't feel like being among them or when they tell me they're going to a party today, let's go. I don't have such interests any more." (Hester)
"Die VIGS takel dit maak my gedaan, dit voel nie ek moet vriende het nie. Ek moet nie met ander mense kommunikeer nie, ek moet net met my twee kinders wees... ek is nie meer soos altyd gaan uit my eie uit... nee ek sit net so by die huis naweke ek sit net by die huis, ek doen my huiswerk ek sit. Ek het nie meer daai gevoel meer soos eers soos ek hom eers gehad het nie. Soos met vrinde of so, ek voel nie om tussen hulle of as hulle vir my sê hulle gaan vandag na 'n partytjie toe, kom ons gaan. Ek het nie meer sulke belangstellings nie." (Hester)

"Mmm, am just at home I don't go around or so, just sit like that..." (Bertha)
"Mmm, is net by die huis ek loop nie so rond nie of so nie, sit net so..." (Bertha)

Nossie explained how she lost interest in social and sport activities after her diagnosis:

"...that which I used to do, I don't do at all any more. Because it felt to me this sickness is now, I now have the sickness and can't do what I would have liked to do. Like for example I used to be interested in sport, I played netball. And and it it's just completely gone." (Nossie)
"...dit wat ek gedoen het, dit doen ek glad nie meer nie. Want dit het vir my gevoel hierdie siek is nou, ek het nou die siek en kan nie doen wat ek graag wil gedoen het nie. Soos byvoorbeeld ek het in sports belang gestel, ek het netbal gespeel. En en dit dit is sommer heeltemal net weg." (Nossie)

Visible illness symptoms of HIV/AIDS such as weight loss, swollen glands and sores on the face or body caused certain participants in the present study to isolate themselves from others. Elna and Hester, who had visible sores and abscesses on their bodies, found it difficult to explain their condition to others and therefore preferred not to socialise:

"...last week I didn't walk at all, because it's on my hip and it just got so swollen last night then I just had to lie lie lie. Kept doctoring it, put betadine cloth on it and so on, but besides when my face looks like that then I'm very ashamed of walking outside. Because many people ask gosh but why does your face look like that and what must I say. Because many people ask questions, see what her face looks like and things like that." (Elna)

"...verlede week glad nie geloop het nie, want dit is op my heup en dit het net so geswel gisteraand toe moet ek nou net lê lê lê. Aanhou dokter, betadine lap op sit en so aan, maar andersins as my gesig so lyk dan is ek baie skaam om buitekant te loop. Want baie mense vra, haai maar hoekom lyk jou gesig so en wat moet ek sê. Want baie mense vra vrae, kyk hoe lyk haar gesig en dinge soos daai." (Elna)

"And mommy and them understand and then they don't send me out...to the shop or so, because they know my face looks too terrible and I wouldn't want to be outside. And I also say it to them I'm not going out, because see what I look like." (Elna)

"En mammie hulle verstaan en dan stuur hulle my nie uit... winkel toe of so nie, want hulle weet my gesig lyk te terrible en ek sal nie buitekant wil is nie. En ek sê dit ook vir hulle ek gaan nie uit nie, want kyk hoe lyk ek." (Elna)

"...usually I also like chatting to people. When I I and my friends are sitting together and then they ask me, gosh gosh Hester what do you think of the pimples and things that are breaking out on my skin." (Hester)

"...gewoonlik gesels ek graag ook met mense. As ek ek en my vrinde nou bymekaar sit en dan vra hulle vir my, jinne jinne Hester wat dink jy van die puisies en goed wat ek uitslaan." (Hester)

As has been discussed earlier in this chapter, many participants felt very conscious about the loss of body weight. Maggie and Sylvie thought that their weight loss was noticed by their work colleagues and friends. They expected that these people were wondering what caused them to lose such a lot of weight. Maggie felt as if she was becoming a stranger to her work colleagues and friends:

"It sometimes occurs to me as well at work and among my friends and so on. Then I think they also want to ask questions, why am I getting so thin, they don't know me like that and all those things..." (Maggie)

"Dit kom partykeer self by my op ook in die werk en tussen my vrinne en so. Dan dink ek hul wil vrae ook vra, hoekom raak ek so maer, hulle ken my nie so nie en al die dinge..." (Maggie)

Sylvie felt self-conscious about her physique and build, because of losing a lot of weight. Consequently she was anxious about speaking to people and being questioned about her weight loss or illness:

"People who are used to me uh uh probably wonder why does the woman look like that and I I wonder what my physique is like because of my legs, my arms and my face..." (Sylvie)

"Mense wat my gewoond is uh uh wonder seker nou hoekom lyk die vrou so en ek ek wonder hoe my liggaamsbou is oor my bene, my arms en my gesig..." (Sylvie)

"...I was too scared to talk to anybody, because many times some of the people who know me had asked why I was sick and so on... And um I look as if I'm very thin..." (Sylvie)

"...ek was te bang om met iemand te praat, want baie kere het soos van die mense wat my ken my gevra hoekom was ek siek en so aan... En um ek lyk so of ek is baie maer..." (Sylvie)

In correspondence with the experiences of the participants in the present study, many other research studies also found that HIV-infected women experienced a drastic change in life style and socialising patterns (Sarna et al., 1999). Sarna et al. (1999) found in their study, on the quality of life of women with HIV/AIDS, that multiple losses and multiplicities of disruptions in quality of life are a given when living with HIV/AIDS. According to Sarna et al. (1999), in comparing the findings of their study to studies with predominantly male samples, significant differences were apparent. Sarna et al. (1999) pointed out that women indicated more severe problems and psychosocial distress than males with symptomatic AIDS. In a study of quality of life in persons with HIV infection, Wachtel et al. (cited in Rose & Clark-Alexander, 1996) found that women had lower scores than men in areas of role and social functioning and in mental health. These findings suggest that because women feel that they are not succeeding in terms of expectations of ideal womanhood and motherhood they may respond by withdrawing and isolating themselves.

5.4.3 Summary

The above descriptions of the participants' experiences of living with HIV/AIDS show a discourse of immense psychosocial losses. The loss of their self-worth and self-confidence, the loss of their caregiving and reproductive roles, the loss of intimacy, a family life and socialising with others, and the loss of being productive affected them as people, women and mothers in their daily lives. These losses influenced their day-to-day routine and functioning, the management of their illness and thus the overall quality of their lives in a harmful way. Charmaz (1997) described a terminal illness as a "searing disruption, a profound loss" (p.35). According to her, the disruption not only attests to loss of health, it threatens loss of self and way of life. The loss may further force dreaded changes of relationships.

HIV/AIDS meant the loss of self-worth and self-confidence for many participants in the present study. Visible illness symptoms like weight loss and sores / abscesses on the face or body caused participants to feel self-conscious and isolated from others. The participants felt that they had been scarred by the physical symptoms of the illness and this had a detrimental effect on their self-image and womanhood. The participants' experiences seem to be shaped by a perception that a "good" woman has to look physically attractive. These findings may suggest that the participants experienced a severe loss of their womanhood.

The loss of motherhood was also reported, which entailed not being able to care for their children, losing their child to foster care, and not being able to fall pregnant or to have another child. The participants' experiences seem to be informed by an understanding that a mother's most important role is that of reproduction and caregiving. Therefore, the social construction of HIV/AIDS may have powerful effects on a woman's self-image as a mother, for it threatens the standard view of women as reproducers and caregivers.

For the participants in the present study, HIV/AIDS also meant the loss of a way of life and many dreams that they had for themselves and their children. It meant the loss of the

prospect of getting married, settling down, making a home with a partner, and leading a close family life. Given the constructions of womanhood and motherhood in their communities, the illness deprived them of being the "good" woman and mother they were expected to be and what they most likely strove to be themselves. The loss of a normal and satisfying intimate and sexual relationship was also a consequence of having HIV/AIDS for the women participants in the present study. These changed sexualities most probably affected their experience of their womanhood in a harmful way.

The loss of productivity at home and in the workplace, because of fatigue and a lack of motivation, had a negative influence on the daily functioning and role performance of the participants. HIV/AIDS also influenced and changed the life style and socialising patterns of participants. After diagnosis, most of the participants in the present study preferred not to socialise with others as they had done before. Their vigour to interact with others declined and, consequently, they became withdrawn and isolated. According to Charmaz (1997), an illness recasts and redirects people's lives, they lose common interests and no longer share pursuits with friends and associates. As they withdraw to hide or manage their illness, important others slip away from them.

The losses experienced by the participants in the present study correlate well with findings from other studies. According to Withell (2000), a diagnosis of HIV/AIDS for a woman has repercussions in all spheres of her life, resulting in numerous losses, inter alia bereavements, social losses (especially those associated with widowhood as well as being rejected by family and friends), loneliness, low self-esteem, sexual limitations, and loss of direction (future plans). Goicoechea-Balbona et al. (2000) stated, "clinical reports suggest that in addition to the biological challenges of HIV, women living with HIV suffer losses related to body image, sexuality, social affiliation, the mothering role, childbearing potential, and hope for the future" (p.23). The loss of self and the loss of a way of life (a potential normal life) experienced by the participants in the present study caused them severe psychological distress and pain.

Therefore, given the discourses of shame, secrecy, separation, suffering and loss, it is understandable that the participants withdrew from other people and became extremely lonely. It is argued, then, that these discourses implied a discourse of isolation and loneliness. The next section will focus on the participants' experiences of loneliness.

5.5 Loneliness

Loneliness was one of the primary psychosocial concerns experienced by the participants in the present study. The two main types of loneliness that these women experienced were loneliness of emotional isolation and loneliness of social isolation. These terms can be defined as the absence of close emotional attachments and lack of support and understanding from intimate and important others (emotional isolation), and the absence of an accessible and engaging social network and lack of social support and acceptance (social isolation) (Weiss, 1973).

5.5.1 Emotional isolation

Almost all the participants in the present study conveyed the experience of emotional isolation, namely the absence of close emotional attachments and lack of support and understanding from intimate and important others.

Certain participants expressed the absence of close emotional attachments in their lives as follows:

"I'm just alone all the way, so people can think of me what they will… regardless of whether I now have the illness or not… I don't have friends Elsa I don't have friends… Most of the time I'm just at home, because H (her boyfriend) is at work, mommy is at work, pi (her father) is away from home then I'm just alone." (Elna)

"Ek is maar al die pad alleen, so mense kan dink van my wat hulle wil… ongeag ek nou die siekte het of nie… Ek het nie vrinne nie Elsa, ek het nie vrinne nie… Meeste tyd is ek maar net by die huis, want H (haar mansvriend) is in die werk, mammie is in die werk, pi (haar pa) is van die huis af dan is ek maar alleen." (Elna)

"I never have real friends at Koelenhof, what I now feel is no I just chat lightly. I will sit a bit there with the one and chat and so on about everyday things, but (she) will never know what inside what is really my problem… I… many times then I uh then I feel I I'm now totally empty… I have the feeling that um it's always on me or something like that… I don't really have girlfriends there, with whom I can chat intimately or so." (Sylvie)

"Ek het nooit regtige vriende op Koelenhof nie, wat ek nou voel nee maar ek sal nou is nou net so gesels. Ek sal 'n bietjie daar by die een sit en gesels en so aan so alledaags, maar sal nooit weet wat binne wat regtig my probleem is… Ek… baie kere dan uh dan voel ek ek is nou is ek heeltemal leeg… ek het die gevoel of um dit is altyd op my of so… Ek het nie regtig vriendinne daar nie, met wie ek nou sal lekker intiem gesels of so." (Sylvie)

"I don't really involve myself with them (family members), I just sit alone that side. Then I just watch TV, I'm not worrying… but I don't really have pals here… No I'm just so alone… alone alone all alone… When I sit so quietly alone then I talk so alone out of myself so alone. Then I think oh dear why should this be happening to me so on. God help and so on with my weak body. There's nobody, just me alone with God alone, I'm walking the road… There's nobody nobody." (Bertha)

"Ek worry ook eintlik nie met hulle (family members) nie, ek sit maar eenkeer alleen daai kant. Dan kyk ek maar TV, ek worry mos nie… maar ek het nie eintlik chommies hier nie… Nee ek is maar so alleen… alleen alleen stoksiel alleen… As ek so alleen stil sit, dan praat ek so alleen uit my eie uit so alleen. Dan dink ek ai hoekom moet dit dan met my gebeur so aan. Here help en so aan met my swak liggaam. Daar's niemand nie, net ek alleen met God alleen, stap ek die pad… Daar's niemand niemand nie." (Bertha)

"I don't feel like going anywhere any more. I don't even feel like walking around, not at all. Sometimes I just stare into the blue, then I just want to sit apart, sit alone and think…" (Maggie)

"Ek is nie meer lus om iewers heen te gaan nie. Ek het nie eers lus om rond te loop nie, glad nie. Partykeer dan staar ek net in die bloute in, dan wil ek net eenkant sit, alleen sit en dink…" (Maggie)

"Because see they are chatting, going dancing and me, then I just sit there. I feel so withdrawn don't have company and so." (Ann)

"Want kyk hulle gesels, loop dans en ek, dan sit ek maar net daar. Ek voel so terug het nie geselskap en so nie." (Ann)

"When I'm on my own again, then I think of it (the illness)… then I went to my room, then I cried myself to sleep…" (Mariana)

"*As ek weer allenig is dan dink ek daaraan (die siekte)… toe gaan ek na my kamer toe, toe gaan huil ek my aan die slaap…" (Mariana)*

The above findings correlate with data from a study conducted by Hackl et al. (1997) on women with HIV/AIDS. Hackl et al. (1997) reported that perceived feelings of emotional isolation were consistently mentioned by the HIV-infected women who participated in their study, primarily because they did not have important others with whom to share their fears and feelings.

Many of the participants in the present study experienced emotional isolation because of a lack of understanding and emotional support from their partners:

"In the beginning stage the relationship between the two of us was very good. And after this child came into our life it seems to me, since the illness since he heard about the illness also, that there is now a whole difference. It's really him he (her child's father) doesn't show his interest… You know Elsa, sometimes I feel like I can do something to him. Understand Elsa, he makes me so deeply angry, because I have to stand so alone while it's our problem for the two of us." (Nossie)

"In die begin stadium was ons twee se verhouding baie goed. En na hierdie kind in ons lewe gekom het lyk my is daar, vandat die siekte vandat hy gehoor het van die siekte ook lyk my is daar nou 'n hele verskil. Dis rêrig hy hy (haar kind se pa) toon nie sy belangstelling nie… Weet jy Elsa somtyds voel ek so ek kan iets doen aan hom. Verstaan Elsa, hy maak my so innig kwaad, want ek moet so alleen staan terwyl dit ons altwee se probleem is." (Nossie)

"He (boyfriend) gives me little support when I'm ill. He doesn't care at all, because my auntie said to him the Saturday when she went to see him the last time, phone the ambulance. Hey, you have to come here constantly with your phoning your phoning, just let the thing die (using the synonym for "die" that refers to animals), he ranted… He said just let the thing die." (Joeyce)

"Hy (mansvriend) gee my min ondersteuning as ek siek is. Hy gee glad nie om nie, want my antie sê toe die Saterdag wat sy hom die laaste keer gaan sien, bel die ambulans. Hey jy moet aanmekaar met my kom met jou bellery jou bellery, laat die ding sommer vrek, sak hy af… Hy het gesê laat die ding sommer vrek." (Joeyce)

"Sometimes and then I don't feel sympathy for him, because he's still busy with women and so on. Then I say to him good heavens S (her husband), don't carry on like that, you know what position we're in. And then sometimes he fights so and the relationship is not really good between the two of us…" (Rosy)

"Somtyds en dan voel ek met hom nie, want hy is nog altyd besig met vroumense en so aan. Dan sê ek vir hom jinne S (haar man) moenie so aangaan nie, jy weet waar in 'n posisie is ons. En somtyds dan baklei hy so en die verhouding is nie eintlik goed nie, tussen ons twee nie…" (Rosy)

According to Sarna et al. (1999), marital status has a significant impact on quality of life for women with symptomatic HIV. In various research studies it was found that women who were married or living with a partner experienced greater anxiety and symptom distress than those with HIV/AIDS who lived alone (Sarna et al. 1999). Similar to other chronic, incapacitating illnesses, the demands of a marital relationship and caring for children may be overwhelming in the face of progressive illness. In the literature it is emphasised that disadvantaged women with HIV/AIDS face additional stresses and adversity compared to men, because of their subordinate position in society and the heavy burden of their care-providing roles.

Many participants also complained about their partners not supporting them financially. This caused participants to feel alone in providing for basic household needs:

"I told him (her child's father)... look after your child and give your child money..., then he gave the child no money and that... Because he doesn't want to work, he wants to spend all his time hanging around in the streets, because I'm working..." (Bertha)

"Ek het vir hom (haar kind se pa) gesê... kyk na jou kind en gee jou kind geld..., toe gee hy vir die kind niks geld en daai nie... Want hy wil mos nie werk nie, hy wil heeltyd op strate loop, want ek werk mos nou..." (Bertha)

"He (her husband) sometimes used to give me what he worked for, before we found out about HIV, he gave me his whole salary, but now that he's getting a grant, he gives perhaps R 150 perhaps... What he used to do for me, doesn't happen any more." (Rosy)

"Hy (haar man) het somtyds vir my wat hy gewerk het, voor ons uitgevind het van HIV, het hy vir my sy hele salaris gegee, maar nou wat hy nou 'n toelae kry, gee hy miskien R150 miskien... Wat hy eers vir my gedoen het, gebeur nie nou meer nie." (Rosy)

Certain participants, like Ann and Mariana, conveyed that because of their partners' substance abuse they were unable to give them the practical and financial support that they needed:

"He (respondent's spouse) doesn't do his bit as man in the house. But now recently he drinks almost every evening and weekends he lies drunk. And it's a big problem..." (Ann)

"Hy (respondent se eggenoot) staan nie sy kant as man by in die huis nie. Maar nou in die laaste tyd drink hy omtrent elke aand en naweke lê hy dronk. En dit is 'n groot probleem..." (Ann)

"I'd rather see to it that we have something to eat than I would buy drink, but he (her partner) doesn't understand such things ... Then I have to talk to the housewife in the house then we speak to him together. He doesn't work for me, he hits me..." (Mariana)

"Ek sal eider sorg vir ons vir iets om te eet as wat ek drank moet koop, maar hy (mansvriend) verstaan nie sulke dinge nie... Dan moet ek saam met die huisvrou in die huis praat dan praat ons saam met hom. Hy werk nie vir my nie, hy slat my..." (Mariana)

McDonnell and Gielen (2003) reported that issues relating to HIV, such as loneliness, economic dependence, substance use/dependence and low self-esteem, were themes often found in the transcripts of the HIV-positive women who participated in their study.

Some participants in the present study, like Ann and Nossie, complained that their partners offered them little or no support with the care of their children. This caused them to feel alone in being solely responsible for the well-being of their children:

"We don't really talk about it (their illness), because I can't talk to him... it's very difficult. He's very difficult, how can I say, he has a temper... that's how he is. No, my husband is just... he doesn't really assist me. Yesterday whenever I said I'm... I said I'm nursery school teacher, I'm I'm teacher, I'm class teacher, I'm mom, I'm dad, I'm everything... I have to do everything... I'd like things to change a bit in the house. My husband to stop his drinking, that's how I feel. He must for once fulfil his male duties, then the two of us can assist each other. I mean he took us out a lot in the past, it doesn't happen any more. And there's money and money for drink. I have I've at times intended leaving him, honestly..." (Ann)

"Ons praat nie eintlik daaroor nie (hul siekte), want ek kan nie met hom praat nie... dit is baie moeilik. Hy is baie moeilik, hoe kan ek sê hy is van humeur... so is hy. Nee wat, my man is maar... hy staan my nie eintlik by nie. Gister wanneer het ek gesê ek is... ek het gesê ek is kleuterskool onderwyser, ek is ek is onderwyser, ek is klasjuffrou, ek is ma, ek is pa, ek is alles... ek moet alles doen... Ek sal graag wil hê dinge moet 'n bietjie verander in die huis. My man sy drinkery los, dis hoe ek voel. Hy moet 'n slag sy manlike pligte nakom, dan kan ons twee mekaar bystaan. Ek meen hy het ons baie uitgeneem annerdag, dit gebeur nie meer nie. En daars geld en geld vir drank. Ek het, ek was al van plan om hom te los, rêrig waar..." (Ann)

"When it's school functions and such things, it's mommy, meetings it's mommy, church is mommy... he's a very poor husband, honestly... When it's anything, it's mom, mommy, mommy. It's not daddy or such. When I can fix something, I fix it..." (Ann)

"As skool funksies en sulke goed is, is dit mammie, vergaderings is dit mammie, kerk is mammie... hy is maar 'n baie swak man, regtig waar... As dit is iets is, is dit ma, mammie, mammie. Dit is nie daddy of so nie. As ek iets kan reg maak, dan maak ek dit reg..." (Ann)

"It's an on-and-off relationship, it's not really a relationship, because he (her child's father) doesn't support me, he doesn't help me with those little things. Like my child lying in the hospital at the moment, he's only been to her once... The little interest he has in his child. He he supports me very little, honestly he supports me very little. You know sometimes I feel like I can do something to him. Understand, he makes me so deeply angry, because I have to stand so alone while it's our problem for the two of us... He must just give me a bit of love and a bit of support and that's all..." (Nossie)

"Dit is 'n aan en af verhouding, dit is nie eintlik 'n verhouding nie, want hy (haar kind se pa) ondersteun nie vir my nie, hy help nie vir my met daai klein dingetjies nie. Soos wat my kind nou op die oomblik in die hospitaal lê, was hy net een keer daar by haar... Die min belangstelling wat hy het aan sy kind. Hy hy ondersteun my baie min eerlik waar hy ondersteun my baie min. Weet jy somtyds voel ek so ek kan iets doen aan hom. Verstaan, hy maak my so innig kwaad, want ek moet so alleen staan terwyl dit ons altwee se probleem is... Hy moet net 'n bietjie liefde en bietjie bystand vir my gee en dis al..." (Nossie).

Broun (1999) and Hudson et al. (2003) emphasised that the majority of women living with HIV in low-income communities bear the responsibility for childcare, housekeeping and health management, without much support from partners or family members. Pienaar (2003) stated that women are often solely responsible for rearing and taking care of children, since their partners are absent or deny responsibility. These findings again show a highly gendered discourse of women being expected to be the primary caretakers of children.

Some participants in the present study experienced emotional isolation because of verbal and physical abuse inflicted on them by their partners:

"He hits me dangerously. It was not the first time that I lay here, before he hit my leg so that it broke he had hit me into hospital with a walking stick." (Joeyce)

"Hy slaan my sommer gevaarlik. Dit was nie die eerste keer wat ek hier gelê het nie, voordat hy my been afgeslaan het het hy my hospitaal toe geslaan met 'n kierie." (Joeyce)

"I started drinking, things I didn't do before. It led later on to him (her husband) fighting with me and he hurt me and we appeared later before a welfare before a social worker." (Hester)

"Ek het beginne drink, dinge wat ek nie gedoen het nie. Dit het lateraan gelei dat hy (haar man) met my gebaklei het en hy het vir my seergemaak en ons het later voor 'n welsyn voor 'n maatskaplike werkster tevoorskyn gekom." (Hester)

Even though these participants endured serious abuse, none of them actually left their partners. Sylvie was the only participant that was already separated from her husband before her diagnosis, although he still verbally abused her. McDonnell et al. (2003) reported that the women participants in their study believed that they were not worthy of a better intimate relationship because of their HIV-status, and that they were compelled to stay with their abusive partner for fear of being totally alone. In the present study this fear was not explicitly voiced by the participants, although it was clear that all of them experienced loneliness.

In the study conducted by Kimerling et al. (1999) they found that HIV-infected women who reported abuse seemed to have additional psychological symptoms, greater distress regarding their physical symptoms, and poorer health status. Brady et al. (2002) and De Marco and Johnson (2003) emphasised that HIV-infected women who experience ongoing abuse may not be empowered to make the best choices to manage their illness and enhance their health status. Victims of abuse are often reluctant to ask for help and to use existing support services, owing to shame, low self-esteem / self-worth and fear for further abuse. Consequently, they become more isolated and lonely. It can be argued that abused women with HIV/AIDS will most probably experience higher levels of loneliness than non-infected abused women, because of the shame and stigma attached to the illness as well.

Of all the participants in the present study, only Hester and Maggie narrated that their partners gave them emotional support which encouraged them to handle their illness more positively:

"Elsa, I've discovered it since he (her husband) and I talk to each other more and talk about the illness and we understand each other better. We're not quarrelsome with each other and insulting towards each other like the other times. We always try giving each other a good word or I also say to him you're getting fat or he says to me you're getting rather fat. We always try saying something good to each other." (Hester)

"Elsa, ek het dit uitgevind vandat ek en hy (haar man) meer met mekaar gesels en praat oor die siekte en ons verstaan meer mekaar. Ons is nie soos die ander tye bakleierig met mekaar en beledigend teenoor mekaar nie. Ons probeer mekaar altyd 'n goeie woord gee of ek sê ook vir hom jy raak nou vet of hy sê vir my jy raak nogal nou vet. Ons probeer altyd om vir mekaar iets goed te sê." (Hester)

"After this (HIV-diagnosis) P (her boyfriend) encouraged me not to take the problems on my shoulders alone, because he supports me... He gave me all encouragement and made my heart strong so that I was just determined. I have it (HIV) and he'll support me through death and life. And P (her boyfriend) is, I love P, his support is very good." (Maggie)

"Na dit (HIV diagnose) toe het P (haar mansvriend) vir my aangemoedig om nie die probleme op my alleen te vat nie, want hy ondersteun my... Hy het my alle aanmoediging gegee en my hart sterk gemaak dat ek net vasbeslote was. Ek het dit (HIV) en hy sal vir my ondersteun deur dood en lewe. En P (haar mansvriend) is, ek is lief vir P, sy ondersteuning is baie goed." (Maggie)

In research comparing sources of social support, support from a spouse/romantic partner has been consistently positively associated with psychological adjustment (Ciambrone, 2002; Walen et al., cited in Schrimshaw, 2003). In the present study the majority of the participants lacked care and support from their partners and this led to psychological distress such as loneliness.

Furthermore, participants narrated that they felt rejected and isolated by their families, especially their mothers, because they did not give them the care and support they needed:

"The welfare people also told me Sister W will pay my money, she (her mother) will buy clothes and food for me, but she doesn't do it. If I go down home and I go and ask for food, then they scold me... They never buy me anything from my own money... She (her mother) buys for herself and the other children in the house... things with my money. Last Christmas I bought nothing, I don't have money... She assists the others and then... she doesn't care about me at all..." (Mariana)

"Die welsyn mense het ook vir my gesê suster W sal my geld pay, sy (haar ma) sal vir my klere koop en kos koop, maar sy doen dit nie. As ek af gaan huis toe en ek gaan vra vir my kos dan skel hulle my uit... Hulle koop my nooit niks van my eie geld nie... Sy (haar ma) koop vir haar en die ander huis kinders... goed met my geld. Nou met Krismis het ek niks gekoop nie, ek het nie geld nie... Sy staan die ander by en dan... sy gee niks vir my om nie..." (Mariana)

"No, I don't concern myself with my mother and them, it's bad luck.. Sister I can't say anything, there's nobody who helps me..." (Bertha)

"Nee, ek worry mos nie met my ma-hulle nie, dis bad luck... Suster ek kan niks sê nie, daar is niemand wat vir my help nie..." (Bertha)

For Hester and Elna it felt as if they were abandoned by their parents, especially their mothers:

"She (her mother) makes me she makes me feel as if I don't belong to them as if I'm someone else's child. I say this to her Elsa, she makes me feel as if I'm her adopted child, because if I ask her for a thing that's nice she always refuses, but she gives to other people." (Hester)

"Sy (haar ma) laat vir my sy laat vir my heel voel of ek nie aan hulle behoort nie of ek iemand anders se kind is. Ek noem dit aan haar Elsa, sy laat my voel of ek haar aannemingkind is, want as ek vir haar 'n ding vra wat mooi is dan sy weier altyd, maar sy gee vir ander mense." (Hester)

"But I can't go to my parents, because I I now how can I say I don't even know any more if there is a relationship of daughter and parents between me and my parents. Because to me it's as if they don't treat me like a daughter of theirs any more..." (Elna)

"Maar ek kan nie na my ma-hulle toe gaan nie, want ek ek hoe kan ek nou sê ek weet nie eers meer of daar 'n verhouding as dogter en ouers is tussen my en my ma-hulle nie. Want vir my is dit hulle behandel my nie meer as 'n dogter van hulle nie..." (Elna)

Elna was also dissatisfied with family members for not giving her the opportunity to express her feelings and, consequently, her needs could not be validated:

"It's just H (her boyfriend) who doesn't want to understand me when I speak to him and my parents also don't want to understand... they don't want to listen they never give me a chance to myself me now how can I say, to explain how I feel about the story (that she is HIV+). If there uh uh is more scolding about something they don't like then they say their say, but if I want to say something then they don't give me a chance to say it. And that's what hurts me very much." (Elna)

"Dit is net H (haar mansvriend) wat my nie wil verstaan as ek praat met hom nie en mammie-hulle wil ook nie verstaan nie... hulle wil nie luister nie hulle gee my nooit kans om myself my hoe kan ek nou sê, te verduidelik hoe ek voel oor die storie nie (dat sy HIV+ is). As daar uh uh nog skel kom oor iets wat hulle nie van hou nie dan sê hulle nou hulle sê, maar as ek nou iets wil sê dan gee hulle my nie kans om dit te sê nie. En dit is wat my baie seermaak." (Elna)

For Hester and Elna the rejection and abuse inflicted on them by their families were so severe that they considered moving away from them and living somewhere else:

"... it feels to me that they (her family) don't care for me, because by just calling me names to my face and then they think nothing of it... It feels I just feel Elsa it would be much better for me if I go away from my family... If P (her husband) and I and my little girl and my little boy are just away from them and could live among other people, we would be much happier, Elsa." (Hester)

"... dit voel vir my hulle (haar familie) gee nie vir my om nie, want deur vir my sommer sleg te sê in my gesig en dan niks dink hulle daarvan nie... Dit voel ek voel net Elsa dit gaan vir my baie betere is as ek weggaan van my familie af... As ek en P (haar man) en my dogtertjie en my seuntjie net weg van hulle af is en tussen ander ander mense kan bly, dan gaan ons baie gelukkiger wil wees Elsa." (Hester)

"Away from my family, away from my family. I think of this the whole time, the only thing that's going to help me is to get away from my family, because they are going to push me into the into the into the grave. They are already doing it. I feel because of it they are going to cause my death..." (Elna)

"Weg van my familie af, weg van my familie af. Ek dink aldag daaraan, al wat my gaan help is om weg van my familie af te kom, want hulle gaan my in die in die in die graf in druk. Hulle doen dit nou al klaar. Ek voel daaraan hulle gaan my dood veroorsaak..." (Elna)

Sylvie decided not to live with her family, because she felt she would be shunned and abandoned by them:

"I don't think I would really be able to live there... perhaps because our family among themselves, they don't communicate well... But I would feel more rejected down there than here... I feel I can't live there (with family and children)." (Sylvie)

"Ek dink nie ek sal regtig kan daar bly nie... miskien omdat ons familie onder mekaar, hulle nie goed kommunikeer nie... Maar ek sal meer uitgestoot voel daar onder as hier... Ek voel dat ek kan nie daar (by familie en kinders) bly nie." (Sylvie)

Although Joeyce was the only participant in the present study that received a lot of support from her mother, she was nevertheless told by her that if she fell ill she would have to find care somewhere else:

"But she (her mother) told me if I get ill they would have to put me in a place, because I can't stay there. Because our house just has two rooms and he (boyfriend) and I sleep in the kitchen. And mommy has said it can't go on like this and if I now really get ill, I would have to get out because I'm going to thingummy (infect with the virus) my child." (Joeyce).

"Maar sy (haar ma) het vir my gesê as ek siek raak moet hulle vir my in 'n plek sit, want ek kan nie daar bly nie. Want ons huis is net 'n tweevertrek en ek en hy (mansvriend) slaap in die kombuis. En mammie het gesê dit sal nie so kan aangaan nie en as ek rêrig nou siek raak dan sal ek moet uit, want ek gaan my kind dingese (aansteek met die virus)." (Joeyce)

A number of studies have found that friend support and family support are positively associated with psychological adjustment (Ciambrone, 2002; Dean et al., cited in

Schrimshaw, 2003). Ciambrone (2002) found in her study that family closeness clearly helped lessen the blow of HIV for women; knowing that they were loved and appreciated helped them maintain positive senses of self. She stated further that parents, especially mothers, could be a key source of care and support for many women. On the contrary, unsupportive interactions from friends, a lover/spouse and mainly from family had an adverse effect on depressive symptoms and psychological adjustment and coping of women with HIV/AIDS (Schrimshaw, 2003). Schrimshaw (2003) stated that women who experience unsupportive interactions from multiple sources are likely to experience more depressive symptoms than women who experience unsupportive interactions from only one source.

In the present study the majority of the participants lacked support and care from important others, such as their partners and mothers, as well as close family members, and this caused them to experience high levels of emotional isolation and distress. In the literature it is stated that people with AIDS become significantly more depressed and lonely than those with other terminal illnesses such as cancer. According to Torres (cited in Sherr, 1995), people with AIDS needed to talk about their losses while the cancer respondents analysed their grief. People with AIDS also indicated a greater need for family and peer support. Given a discourse of HIV/AIDS as an incurable and deadly illness and a discourse of HIV/AIDS as a shameful illness that someone should be blamed for, it can be argued, then, that for the participants in the present study the need for support and care was rarely satisfied. Therefore, it may be suggested that HIV/AIDS does not elicit the same amount of support, company and care as other terminal illnesses. Consequently, this may lead to further emotional and social isolation.

5.5.2 Social isolation

According to the participants in the present study, the stigma attached to HIV/AIDS and people's fear of getting infected with the virus were the main reasons why family, friends, and members from their community rejected them, which led to social isolation and the

loss of a social life (see section 5.4.2.3). Furthermore, owing to the various and serious losses the participants experienced, they withdrew and socially isolated themselves from others. Consequently, the participants were to a great extent deprived of regular and normal interaction with and acceptance from others, and deprived of an accessible and supportive social network.

Rosy verbalised how the loss of companionship and attention from others made her feel very isolated. Because of being HIV-infected her basic human need to communicate and be in contact with people as before was not satisfied:

"Yes sometimes I feel it, feel very alone without people... How people are and because of you who have HIV, they aren't interested. Now this this worried me a lot and so on, oh dear it's HIV and so, now the people aren't interested in you. Now it's just your husband and your child. Sometimes I would like so much to talk to them, but because they know that you have HIV, they don't care about you any more..." (Rosy)

"Ja somtyds voel ek dit, baie alleen voel sonder mense... Hoe is die mense en oor jou wat nou HIV het, hulle stel nie belang nie. Nou dit dit het my baie bekommer en so, ai dis mos HIV en so, nou stel die mense nie belang in jou nie. Nou is dit net jou man en jou kind. Somtyds wil ek so graag met hulle praat, maar wat hulle nou weet dat jy nou HIV het, worry hulle nie meer oor jou nie..." (Rosy)

Nossie and Hester explained that HIV/AIDS is so stigmatised that people avoid having any physical contact with an infected person. This caused them to stay indoors and not communicate with others:

"Or I visit people and I drink out of their cups and then many people of course have a very negative view of this sickness. Take it very negatively you know, you're not allowed to use this or to use that and that type of thing. That's why I rather just stay in my house." (Nossie)

"Of ek kuier by mense en ek drink uit hulle koppies uit en dan baie mense is mos baie negatief opgevat deur deur hierdie siek. Vat mos baie negatief op, jy mag nie dit gebruik nie of dat gebruik en daai tipe ding. Dis hoekom ek in my huis maar bly." (Nossie)

"...because I just look at them then I also see that, how they how they are towards me and how they, in their whole attitude I can see they want to be a bit a bit away from me. Or they don't want to wash with me out of the same thing or do such and such. They are away from me... They don't want to drink with me from a cup of water or something like that." (Hester)

"...want ek kyk net vir hulle dan sien ek ook die, hoe hulle hoe hulle teen teenoor my is en hoe hulle, in hulle hele houding kan ek sien hulle wil 'n bietjie 'n bietjie weg van my af wees. Of saam met my in een ding uit

was of so so maak nie. Hulle is weg van my af... Hulle wil nie saam met my uit 'n koppie water drink of so nie." (Hester)

For Sylvie, even when she was in the company of other people she felt removed and isolated from them and felt constantly lonely:

"That I'm not totally there... um there are some (times) that I can be among people and then I'm just totally um I feel just totally far away from them. I feel the whole time just that um... I'm alone..." (Sylvie)

"Dat ek nie heeltemal daar is nie... um daar is sommige wat ek kan tussen mense wees en dan is ek net heeltemal um voel ek net heeltemal weer ver van hulle af. Ek voel die heeltyd maar net um... ek is alleen..." (Sylvie)

According to Weiss (1973), anything that leads to loss of contact with those who share one's concerns, like social stigmatisation and prejudice, may give rise to social isolation. Dukes and Denny (1995) emphasised that a fatal illness such as AIDS, which is accompanied by much suffering, creates greater perceived danger of contact and increases social prejudice and distance. In the present study the narrations of the participants show that they were rejected in a physical as well as emotional way. People ignored them, and verbally abused them, but also did not want to have any physical contact with them. Thus, again the experiences of these women seem to be informed by an understanding that HIV/AIDS is a deadly illness that one should be ashamed of and be blamed for. These experiences of being "bad", shameworthy, and not deserving caused the participants in the present study to be very lonely. It is hard to comprehend the severe levels of loneliness and emotional suffering these participants must have experienced, because of being emotionally and physically rejected to such an extreme degree.

Many participants in the present study felt alone in caring for their children and expressed a need for practical and financial support. Nossie narrated that there was no one to relieve her of her motherly duties:

"I'm her mother I must do it, because if I don't do it then who else is going to do it. Because there's nobody who can relieve me with her. Because I believe in that at home, when she's at home, if she wakes up her mother is just there with her. There's no one else who picks her up, it's only just it's only just mom." (Nossie)

"Ek is haar ma ek moet dit doen, want as ek dit nie doen nie dan wie anders gaan dit dan doen. Want daar is nie een wat my kan aflos by haar nie. Want ek glo daaraan by die huis as sy by die huis is, as sy wakker

skrik is haar ma maar daar by haar. Daar is niemand anders wat haar optel nie, dit is maar net dit is maar net ma." (Nossie)

Bertha and Nossie related that they had no practical support at times when they desperately needed it to care for an ill child:

"There's nobody nobody. I don't ask if they don't want to, can just leave it then I walk…If the little one is ill it's getting late, then I walk up here to the hospital… But I don't really find friends people who live in the Dal, who have transport or so… I don't find any, we walk there round the side of the town. We walk, my baby little boy and I…" (Bertha)

"Daar's niemand niemand nie. Ek vra nie as hulle nie wil nie, kan maar los dan stap ek… As die enetjie nou siek is dit raak nou laat, dan stap ek hier op hospitaal toe… Maar ek kry nie eers eintlik vrinde mense wat in die Dal bly nie, wat rygoed het of so nie… Ek kry nie, ons stap daar by die dorp se kant om. Ek stap, ek en my baby klonkie…" (Bertha)

"No nobody I'm the only one. If she gets sick I have to go and look for transport myself to bring us to the hospital and such. There's nobody really who gives who gives me a breather, I take her and you also rest a little bit. I do this so there's nobody there is really nobody… I'm her mother I have to do it because if I don't do it then who else is going to do it. Because there's nobody who can relieve me with her." (Nossie)

"Nee niemand nie ek is maar al een. As sy siek raak moet ek maar self 'n ryding gaan soek om vir ons hospitaal toe te bring en so. Daar is niemand eintlik wat my wat vir my 'n kansie gee, ek vat vir haar en rus jy bietjie ook. Ek doen daai so daar is niemand daar is niemand rêrig waar… Ek is haar ma ek moet dit doen, want as ek dit nie doen nie dan wie anders gaan dit dan doen. Want daar is nie een wat my kan aflos by haar nie." (Nossie)

Data obtained by Williams (1995), correlate well with findings from the present research study that low-income women with HIV are socially isolated from support services by factors such as unemployment, being single mothers, lack of convenient transportation, and substance abuse. Catz et al. (2002) stated that distressed women with HIV/AIDS might have poorer health outcomes if they have problems with utilising existing support services and getting to medical appointments.

Many participants narrated that they had little practical and financial assistance from others. This made them feel very alone in providing for the basic needs of their children and families:

"I don't feel good, because there aren't people who help me…" (Mariana)

"*Ek voel nie goed nie, want daar is nie mense wat my help nie…" (Mariana)*

"Nobody helped me, just now and then I greet the people and then I talk, don't they perhaps have a job for me and so… Now I think oh dear, where am I going to get food for the evening or so. Now I walk and then I go and ask the people to give me something for the pot or so. Sometimes I get, sometimes it's insults." (Rosy)
"Niemand het vir my gehelp, net nou en dan groet ek die mense en dan praat ek, het hulle nie miskien vir my 'n werk nie en so… Nou dink ek ai jinne waar gaan ek nou kos kry vir die aand of so. Nou stap ek en dan gaan vra ek vir die mense om vir my iets vir die pot of so. Somtyds kry ek somtyds is dit beledigings." (Rosy)

"If they can eat and they can be clean, then I feel happy. But if I don't have soap I have nothing I can do for them. Then I feel so why don't I take them and just go away from the place, but… but where must I go Elsa." (Hester)
"As hulle kan eet en hulle kan skoon wees, dan voel ek gelukkig. Maar as ek nie seep het nie het ek niks wat ek vir hulle kan doen nie. Dan voel ek so hoekom vat ek hulle nie en gaan net weg uit die plek uit, maar… maar waarheen moet ek gaan Elsa." (Hester)

"She (her mother) is also not um well, she is also sickly (subject sniffs) and she's getting old… And she's the only one who works for us at home… there's not another income that can help us…" (Sonja)
"Sy (haar ma) is ook nie um gesond nie, sy is ook sieklik (subjek snuif) en sy raak al oud al… En sy is al een wat vir ons werk in die huis… daar's nie nog 'n ander inkomste wat vir ons kan help nie…" (Sonja)

"Sometimes I would tell them that I um just feel I'm deteriorating, my children are deteriorating, because I uh drink too much perhaps and there is and um I alone have to work. And um there is so much that I lack, there is so much that my children lack… and I can't do it all for them I can't do it all myself." (Sylvie)
"Partykeers sal ek vir hulle sê dat ek um voel net ek raak agteruit, my kinders raak agteruit, want ek uh drink miskien te veel en daar is en um ek is alleen wat moet werk. En um daar is so baie wat ek kort kom, daar is so baie wat my kinders kort kom… en ek kan dit nie alles vir hulle ek kan dit nie alles self doen nie." (Sylvie)

Charmaz (1997) stated that existing from day to day, like the majority of the participants in the present study, occurs when an ill person plummets into continued crisis that shatters normal life. She stated further that existing from day to day means a constant struggle for daily survival. Poverty and lack of support contribute to and complicate that struggle. Therefore, poor and isolated people usually suffer extremely, and loss of control extends to

being unable to obtain basic necessities, such as food, shelter and medical care (Charmaz, 1997).

The largely impoverished women in the study of Sarna et al. (1999) were also troubled by financial worries. Issiaka et al. (2001) found in their study that the women were concerned about their own and their children's health, income generation, buying consumer goods and basic foods. Most of these women were expecting help with receiving medication as well as financial aid to launch a small business. The women participants in the study of Heath and Rodway (1999) with children under 18 years indicated practical and financial help with childcare among their most urgent needs.

In the literature it is stated that HIV-infected women must simultaneously deal with a life-threatening illness as well as a range of social issues such as victimisation, housing, food and employment. Having not only to manage their own illness, these women usually have to deal with their role as caregivers for their sick partners and children (Segurado et al., 2003). As a result, HIV infection does not become the first priority for these women, because of the fact that their basic needs have not been met (Sowell et al., 1999). The discourse of motherhood that constructs a mother as the primary caregiver may suggest that a poor woman with HIV/AIDS will struggle alone for daily survival.

Some participants, like Rosy, also complained that they lacked information and support from healthcare workers:

"Nobody who shows me about the um HIV, just sometimes we (she and her husband) walk and just ask the people or so... no one has ever talked to us about HIV or so." (Rosy)

"Niemand wat wys my nou van die um HIV nie, is net somtyds wat ons (sy en haar man) nou loop en vra maar vir die mense of so... daar het nog nooit een met ons gesels oor HIV of so." (Rosy)

Sylvie narrated that even at the time of receiving her diagnosis, there was no knowledgeable person she could talk to about her illness:

"Nobody, there was nobody it's just my cousin that I and uh she also didn't really know what to say to me..." (Sylvie)

"Niemand, daar was niemand dit is net my niggie wat ek en uh sy het ook maar nie eintlik geweet wat om vir my te sê nie..." (Sylvie)

Derlega and Margulis (cited in Peplau & Perlman, 1982) illustrated how patients with terminal conditions face terrible uncertainties associated with their illness. Patients who seek to clarify their feelings may become isolated and lonely, because of their own and others' inability to talk about the illness. They may fear that others will reject them if they discuss their illness. According to Derlega and Margulis (cited in Peplau & Perlman, 1982), health professionals may also avoid talking to patients about their illness on account of their own anxieties, which in turn makes it even more difficult for patients to talk about their problems. The absence of an appropriate person with whom to share their emotions and who will protect their intimate disclosures may lead to interpersonal estrangement and loneliness. It is inevitable, then, that if the illness is constructed as a silent one, it will also be a lonely one.

The narrations of the participants in the present study clearly indicate that they were to a great extent deprived of regular and normal interaction with and acceptance from others, and did not have access to a sufficient and supportive social network.

5.5.3 Need for emotional and social support

Even while experiencing immense emotional and social isolation, the majority of participants revealed a strong need for acceptance and support from others:

"…I wish others should also treat me as any other person is treated. I don't want them to look at me with that attention or to pity me. Um yes, I would like them to love me because love is the thing I miss most in my life and then that's what I want for my child as well…" (Elna)

"…verlang ek ander moet ook vir my behandel soos enige ander mens behandel word. Ek wil nie hê hulle moet vir my kyk met daai aandag of my jammer kry nie. Um ja ek wil graag hê hulle moet lief wees vir my, dam liefde is die ding wat ek die meeste mis in my lewe in en dan dis wat ek wil hê vir my kind ook…" (Elna)

"Sometimes I would like so much to talk to them (female friends), but because they know that you have HIV, they don't care about you any more…" (Rosy)

"Somtyds wil ek so graag met hulle (vriendinne) praat, maar wat hulle nou weet dat jy nou HIV het, worry hulle nie meer oor jou nie." (Rosy)

"My expectations are that uh that there will be an improvement in health for me and for my child. And that I will get more support." (Nossie)
"*My verwagtinge is dat uh dat daar beterskap sal kom vir my en vir my kind. En dat ek nog meer ondersteuning sal kry." (Nossie)*

"People (her family) blame, um give us reproaches Elsa, they usually scold me that I don't have TB, I have AIDS and sometimes it hurts me man, sometimes I just feel I must sit apart and just talk to somebody who can support me. Then I feel so powerless then I can do nothing nothing for myself." (Hester)
"Mense (haar familie) verwyt, um gee vir ons verwyte Elsa, hulle skel vir my gewoonlik ek het nie TB nie ek het VIGS en sommige tye dan maak dit my seer man, sommige tye dan voel ek net ek moet eenkant sit en net met iemand gesels wat vir my kan bystane. Dan voel ek so kragteloos dan kan ek vir myself niks niks doen nie." (Hester)

"Then I feel very bad about it, now I'm lying there, who's going to care about me? Who will come and help me perhaps with the child... or perhaps clean the house or so...?" (Rosy)
"Dan voel ek baie sleg oor, nou lê ek daar, wie gaan vir my omgee? Wie gaan vir my kom help miskien met die kind... of miskien die huis skoon maak of so...?" (Rosy)

In a study conducted by Heath and Rodway (1999), the responses to what was needed by respondents at the time of diagnosis pointed strongly to a need for information, a need for someone to listen to their concerns and for someone to "just be there". The primary reason for wanting social support given by the women participants in the study conducted by Hackl et al. (1997) was to have an environment in which they could openly share their fears and feelings with people who were experiencing the same type of isolation and despair. The above citations clearly show that the participants in the present study also needed care, support and understanding from others.

The participants in the present study expressed a specific need for care and support from their partners:

"It must all go well again in the future as it used to be between me and my husband. I just want him to change that's all... That he should just become that which he was. He didn't use to drink like now. When he came from work, he came straight home from work, eat and sleep, bath and sleep. But he's no longer like that, he... makes other rounds and then he comes home. And then he wants food. " (Ann)
"Dit moet alles weer goed gaan in die toekoms soos dit gewees het tussen my en my man. Ek wil net hê hy moet verander dis al... Dat hy net dit moet word wat hy was. Hy het nie gedrink soos nou nie. As hy uit die

werk uit gekom het, dan kom hy reguit uit die werk uit huis toe, eet en slaap, bad en slaap. Maar hy is nie so meer nie, hy… loop nog draaitjies en dan kom hy huis toe. En dan soek hy kos." (Ann)

"My biggest worry is just that I want uh uh me and she (baby daughter) and her dad to be together… he must be able to admit that this which has happened to the three of us, the three of us must now stand together. These are now really my worries. I want him to, he must support the two of us…" (Nossie)
"My grootste kwelling is net ek wil hê lat uh uh um ek en sy (babadogter) en haar pa moet saam wees… hy moet kan erken dat dit wat gebeur het met ons drie, ons drie moet nou saam staan. Dit is my dit is nou rêrig my kwellinge. Ek wil hê hy moet hy moet vir ons twee bystaan…" (Nossie)

"That we that I feel the dad should communicate more with us and communicate less with his friends… he is the roof that has to make sure he is always there when I need him… I honestly miss that very much, Elsa. Because yesterday I felt so good when yesterday morning when he told me that um I can go then he'll come and fetch me. Then I felt so good in my heart." (Nossie)
"Dat ons dat ek voel dat die pa moet meer kommunikeer met ons en minder met sy vriende kommunikeer… hy is die dak dat hy moet sorg dat hy altyd daar is as ek hom nodig het… Ek mis dit baie rêrig waar Elsa. Want ek het gister so goed gevoel toe hy nou gisteroggend toe hy nou vir my sê dat um ek kan gaan dan kom haal hy my. Toe voel ek so goed in my hart." (Nossie)

Certain participants, like Elna and Hester, also narrated their need to be loved, accepted and supported by their families:

"Um yes, I would like them (her family) to love me, because love is the thing I miss most in my life and then that's what I want for my child as well, because I give her much love." (Elna)
"Um ja ek wil graag hê hulle (haar familie) moet lief wees vir my, dam liefde is die ding wat ek die meeste mis in my lewe in en dan dis wat ek wil hê vir my kind ook, want ek gee vir haar baie liefde." (Elna)

"I feel very bad about it, because I feel they're my brothers and sisters and it's not necessary for them to want to be away from me. I didn't ask for the illness Elsa and I ask them also that they should support me."(Hester)
"Ek voel baie sleg daaroor, want ek voel dis my broers en my susters en hulle het nie nodig om van my af… weg van my af te wil wees nie. Ek het nie gevra vir die siekte nie Elsa en ek vra vir hulle ook dat hulle moet vir my bystaan." (Hester)

Sylvie, who lived far away from her family, expressed her longing to communicate with her children and to have a normal family life:

"I probably miss to be able to sit with my children and also um listen to their problems and to be able to talk to each other and so on... we are never together. Just that homeliness to uh be able to be together." (Sylvie)
"Ek mis seker die wat ek om by my kinders te kan sit en ook um hulle probleme aan te luister en met mekaar te kan gesels en so aan... ons is nooit bymekaar nie. Net daardie huislikheid om uh bymekaar te kan wees." (Sylvie)

From the above narrations it seems that womanhood is constructed as being a person who is emotionally involved with her family, a connected person. This may suggest that if she is emotionally separated from her loved ones, she becomes less of a woman and a person.

Extensive literature has demonstrated the influence of social interactions and the accessibility of psychosocial support on psychological adjustment to chronic illness (Wills et al., cited in Schrimshaw, 2003). Hough et al. (2003) found that maternal social support had a strong, positive effect on the use of more healthy and meaningful coping strategies, which resulted in decreased emotional distress in the mothers. According to Wills et al. (cited in Schrimshaw, 2003), supportive social interactions have been found to be positively associated with psychological adjustment to stress and HIV infection. The damaging effects of negative or unsupportive social interactions on psychological adjustment, on the other hand, have also been confirmed among HIV-infected patients (Song et al., cited in Schrimshaw, 2003). Raganya (2003) also found in his study on HIV-infected Black South African women that the more these women received social support, the lower were the levels of depression they experienced.

It is clear from the participants' citations in the present study that they were in need of much more emotional and social support, care and acceptance from others than what they were receiving.

5.5.4 Summary

In the present study the women's citations clearly show that they were extremely lonely on an emotional and social level. From their citations two competing discourses can also be

identified: the construction of the illness as one of isolation and silence, and the construction of womanhood as connected and emotionally communicated. It can be argued then that an HIV-infected woman loses some of her worth as a woman and as a person, because the illness deprives her of connection and language.

Weiss, the leading spokesperson for an interactionist approach to loneliness, stated that loneliness is caused not by merely being on one's own but by being without some definite needed and meaningful relationship, or set of relationships, or connectedness with a coherent and supportive community (Peplau & Perlman, 1982; Weiss, 1973). Weiss (1973) emphasised that loneliness arises when one's social interactions are deficient in supplying crucial social requirements such as attachment, guidance and a sense of worth. This experience of loneliness can be associated with mourning, a depressed mood and anxiety, which results when the diagnosed person withdraws from others out of fear of rejection, or when existing social-support networks withdraw from the person following her HIV-diagnosis (Faithfull, 1997). Friedman and Katz (cited in De Gouveia, 1984) suggested that prolonged or chronic loneliness or repeated rejection, as experienced by HIV-infected persons, leads to self-blame and finally to depression.

According to Cohan and Atwood (1994), Heath and Rodway (1999) and Schlebush et al. (1995) stigma, lack of support and isolation are issues pertaining to the societal context of AIDS that occur throughout the literature. Leenerts and Magilvy (2000) stated that already at the time of diagnosis fear and isolation were common responses for the women participants in their study. This finding correlates with responses of the participants in the present study, who verbalised that at the time of diagnosis they already experienced concerns regarding disclosure, possible rejection and abandonment. At the time of diagnosis many participants in the present study made the decision not to disclose their status to important others, family and/or friends. Consequently, at this early stage and thereafter they isolated themselves on an emotional and social level from others and this deprived them of potential psychosocial support and care. This caused a "checkmate" situation: the participants expressed their serious need for social support and care, but

because of fear of stigmatisation and rejection they isolated themselves from potential help.

In the study conducted by Hackl et al. (1997), the women participants also indicated the same significant areas of social-support concern: a strong desire for support networks and a fear of reaching out because of the ostracism that could follow HIV/AIDS disclosure. Hough et al. (2003) stated that even with the strong tendency toward secrecy, the beneficial effect of social support on emotional distress has been demonstrated repeatedly among samples of HIV-infected women. Murphy et al. (2002) discussed various studies indicating that perceived family and social support are predictive of reduced loneliness, stress, anxiety and depressive symptoms and better management of the illness. However, evidence shows that HIV-infected women, and especially rural, minority or underprivileged women, are lacking in these supportive resources that are known to shield against social stressors and reduces psychological concerns (Sowell et al., 1999).

Goicoechea-Ballbona et al. (2000) emphasised that gender inequality has resulted in the lack of development of gender-specific services for low-income women with HIV/AIDS to combat and manage their illness on a physical and psychosocial level. Sowell et al. (1999) stated that although women face many of the same devastating physical manifestations of HIV/AIDS as men, they also have unique bio-psychosocial issues related to being HIV-infected that should be studied and addressed. Cates et al. and other writers (cited in Hackl et al., 1997) stated that development of effective support services and care is particularly challenging for impoverished women with children, for whom HIV infection is but one of many life stressors. From the literature, as well as from the citations of the participants in the present study, it is clear that the majority of women living with HIV/AIDS are in need of support groups or individual therapy/counselling to deal with the physical progression of the illness and their psychological distress, as well as the stressors and strains within their daily lives, such as poverty, abuse, and family responsibilities. It is thus evident, given the discourses of silence, loss and loneliness, that the participants in the present study were not receiving the psychosocial care and support that they needed.

In the participants' accounts of their illness experience, two dominant discourses can again be highlighted. The first discourse is a discourse of HIV/AIDS, within which the illness is constructed as an incurable and deadly illness; of HIV/AIDS as a shameful illness that someone should be blamed for; and of HIV/AIDS as being associated with silence, separation, suffering, loss, and loneliness. The second relevant discourse is a discourse of mothering, what it means to be a "good" woman/mother and caregiver. The discourse of HIV/AIDS as an illness and the discourse of a "good" woman/mother and caregiver seem to be irreconcilable, because a "good" women and caregiver is constructed as someone who is connected, physically strong, healthy and productive, someone who should primarily take care of her children and family, and not be separated from them, or neglect or abandon them through illness or death.

Consequently, the loneliness experienced by the participants in the present study, accompanied by many other distressful emotions and the lack of psychosocial support and care, had a harmful effect on coping with their illness condition and associated stressors. The next section will focus on the coping strategies used by the participants in the present study.

5.6 Coping strategies

The coping strategies used by the participants in the present study were influenced by their state of loneliness and their lack of psychosocial support. Although the participants in the present study used various strategies to cope with their illness, the coping strategies most often used were secrecy/concealment, withdrawing, and escapism by means of alcohol abuse. These strategies were mainly used to protect themselves from being blamed, shunned and rejected for being HIV-infected. However, by using these strategies they were also avoiding serious issues and stresses related to their illness. Other coping strategies used included faith and prayer, hope for a cure and future, living for their children, socialising, and living healthily.

O'Leary and Helgeson (1997) stated that "the term coping refers to the marshalling of efforts to ameliorate the effects of potentially stressful events" (p.30). The ways individuals cope with specific stressors are often divided into two categories: problem-focused coping and emotion-focused coping (Lazarus & Folkman, cited in O'Leary & Helgeson, 1997). According to these writers, problem-focused coping involves efforts to change the actual stressful situation, whereas emotion-focused coping involves attempts to alleviate the distress response. Examples of problem-focused coping are gaining information regarding the stressor, joining a support group, going for treatment if the stressor is an illness, finding healthy activities to relieve the stress reaction such as starting an exercise routine, and making plans and setting goals for the future. Emotion-focused coping strategies include relaxation, positive reappraisal, distraction, avoidance, distancing, and escapism by means of substance abuse. O'Leary and Helgeson (1997) pointed out that there are different types of problem- and emotion-focused coping. According to them, in the case of emotion-focused coping, there are healthier types (such as positive reappraisal and relaxation) and unhealthier types (such as escapism through substance abuse). O'Leary and Helgeson (1997) stated that, in general, problem-focused coping is more helpful and effective in controllable situations, but in situations where a person has little or no control emotion-focused coping can be beneficial.

The coping literature acknowledges that denial-like strategies such as distancing can be beneficial when nothing can be done about the outcome of a situation (Spies, 2001). Therefore, the usefulness of a coping strategy such as distancing or withdrawing would depend on the context. According to Folkman and Lazarus (cited in Spies, 2001), it is essential to consider the fact that appraisals of conditions as unchangeable are associated with emotion-focused coping. Spies (2001) conducted a study on the coping mechanisms of low-income Coloured women in the Western Cape. She stated that the poverty of the participants' environment in terms of coping resources played a significant role in the prevalent use of emotion-focused coping that was found among the participants in her study. According to Spies (2001), the finding that the coping mechanisms of the participants were not only prevalently emotion-focused, but were also often avoidant of these emotions, needed to be considered in the light of the fact that the participants found

themselves without a voice. She stated, “Not only are these women limited by their environment both in financial terms as well as coping options, but they also find themselves in a context where their emotions are often not taken seriously” (Spies, 2001, p.79). Spies (2001), like other writers, advocated a redefinition of emotion-focused coping, as efforts to be in touch with and deal with one’s emotions, as opposed to “strategies that entail an effort to reduce tension by avoiding dealing with the problem” (Holahan et al., cited in Spies, 2001, p. 88), or as efforts to reduce or manage emotional distress (Folkman et al., cited in Spies, 2001).

According to the above account of coping strategies, it was clear from the descriptions of the participants in the present study that they were inclined to use emotion-focused coping strategies more frequently than problem-focused coping strategies. Despite the different coping strategies employed by these women, many of them related ambivalent feelings regarding the management of their illness. For Hester, there were times that she felt she could cope with her illness and other times she felt she could not cope at all. She explained how her life was divided into “good” times/days and “bad” times/days:

“Sometimes Elsa when I think about the sickness then then I feel I can handle it and other times it feels again that I can’t handle the sickness, because things don’t improve… We have now been living with the sickness for five years and in the five years it has been a struggle and one day we understand it and the next day we don’t understand it.” (Hester)

“Sommige tye Elsa as ek dink oor die siek dan dan voel ek ek kan dit hanteer en ander tye dan voel dit weer ek kan nie die siek hanteer nie, want dinge kom nie reg nie… Ons lewe nou al vyf jaar met die siek en in die vyf jaar het dit sukkel gegaan en eendag verstaan ons dit en die ander dag verstaan ons dit nie.” (Hester)

According to Charmaz (1997), dividing life into “good” days and “bad” days provides one measure of experiencing an intrusive or chronic illness. She explained further that fundamentally, ill people define “good” and “bad” days according to their evaluations of the intrusiveness of illness, which means the relative presence or absence of symptoms. Charmaz (1997) stated that the amount of suffering and ill-health that sick people experience differentiates “good” and “bad” days.

Sylvie conveyed her ambivalent feelings with regard to coping with her illness:

"Um I um… I don't really know what I do to to uh live with it… and if I'm really living with it I don't know… But I don't really know because to me it is so… hopeless to hope for something or to think but I can still so and I can still do something here for my children or for us together. But I um feel like I feel I can't, sometimes I can no longer persevere… I can't persevere." (Sylvie)

"Um ek um… ek weet nie eintlik regtig wat ek doen nie om om uh daarmee saam te leef nie… en of ek regtig daarmee saam leef weet ek nie… Maar ek weet nie eintlik nie, want dit is vir my so… hopeloos om op iets te hoop of te dink maar ek kan nog so en ek kan nog iets doen hier vir my kinders of vir ons saam. Maar ek um voel soos wat ek voel ek kan nie, partykere kan ek nie meer volhou nie… ek kan nie volhou nie." (Sylvie)

Rose & Clark-Alexander (1996) stated that when women are confronted with distress, coping mechanisms become important in managing HIV progression over time. According to these writers when women are not capable of coping effectively with their own HIV infection or that of their children, distress symptoms such as anxiety, denial, depression and anger may be evident. These symptoms may additionally be detrimental to their quality of life. Although the participants in the present study were not (completely) in a state of denial about their illness condition, they consciously concealed it from others. The majority used alcohol to escape, to disconnect, and to forget about their illness and related stressors. Anger was not overtly presented by most of the participants in the present study. However, the narrations of the participants show that anxiety and depressed feelings underlay many coping mechanisms used by them.

5.6.1 Secrecy, concealment and social withdrawal

Although the participants in the present study revealed many coping strategies, secrecy, concealment and social withdrawal were the strategies most often used. All the participants in the present study described their HIV-status as a personal and private matter. Some participants called it their secret. Most of the participants concealed their diagnosis from very close family members, friends and the community because of fear of being stigmatised, rejected and/or victimised (see section 5.2 of this chapter on stigmatisation and fear of disclosure).

Some of the participants described how and why they kept their HIV-status a secret:

"I don't really want them to find out what's the matter with me. It's a secret between me and my boyfriend and God. Do you understand… I don't want to tell this to everybody… I'm scared they're going to besmirch my name." (Maggie)

"Ek wil nie eintlik hê hulle moet uitvinne wat makeer ek nie. Dit is 'n geheim tussen my en my kêrel en God. Verstaan jy… Ek wil nie vir almal dit vertel nie… ek is bang hulle gaan my naam besmadder." (Maggie)

"One chum will tell the other… say to the other have you heard about this. No, one can't with such things share your secret with people." (Joeyce)

"Een chommie sal vir die ander ene vertel… sê die ander ene het jy gehoor van dit. Nee mens kan nie met sulke dinge mense in jou geheim deel nie." (Joeyce)

"Then I'll hear it every day and they'll also not be the same with me any more… but then I think to myself, it's like something holding me back. I mustn't do it, because it'll be the biggest mistake I'll make in my life." (Hester)

"Dan gaan ek dit elke dag hoor en hulle sal ook nie meer met my dieselfde wees nie… maar dan dink ek by myself, dis soos iets wat my weerhou. Ek moet dit nie doen nie, want dit is die grootste fout wat ek in my lewe gaan doen." (Hester)

Sowell et al. (1997) stated that even though a great deal of the research investigating coping styles in HIV/AIDS had focused on men, there was growing evidence that HIV-infected women cope less effectively with their illness than do HIV-infected men. In a study conducted by Hackl et al. (1997) the women participants used coping strategies such as denial, concealment and isolation, to avoid rejection by others and to protect themselves from scorn and judgment. It seems that for low-income women disclosure of an HIV-status can elicit more harmful responses than for men, because within their socio-economic environment women are perceived as powerless and also perceive themselves as powerless and are treated accordingly. The socio-economic environment, therefore, must also be considered as contributing to discourses on HIV/AIDS within which women are disempowered.

In a study conducted by Hackl et al. (1997) the participants used concealment as coping strategy to avoid rejection by others and to protect themselves emotionally. Reasons given by these HIV-infected mothers for the use of concealment as a coping strategy were fears of social rejection and stigma, additional external stressors on their children and

potential abandonment by a partner. As a coping response to emotional distress, participants in this study reported increased intensity and frequency of crying. This behaviour occurred most often when the women were unable to discuss their fears with important others and when denial failed. It seems that the redefinition of emotion-focused coping, as efforts to be in touch with and deal with one's emotions (Spies, 2001), can benefit women with HIV/AIDS.

In the present study many participants kept their own and their children's' HIV-status a secret by withdrawing socially:

"... that what I'm experiencing, that others can see but not know. They see me, but they know nothing about me... Everybody asks me what is really wrong with my child, why is my child so often sick. I can't go and tell them..." (Nossie)

"...dat dit wat ek beleef, dat ander kan sien maar nie weet nie. Hulle sien vir my, maar hulle weet niks van my nie... Almal vra vir my wat makeer my kind dan werklik, hoekom is my kind so baie siek. Ek kan nie vir hulle gaan sê nie..." (Nossie)

"No, no girlfriends to whom I can open my heart... And sometimes I think no, I just keep to myself that's all, just talk only to my little girl... This makes me um that I'm now sometimes so alone, I don't have friends or so." (Rosy)

"Nee niks vriendinne wat ek my hart kan oopmaak nie... En soms dan dink ek nee ek bly net by myself dis al, gesels maar net saam met my dogtertjie... Dit maak my um dat ek nou somtyds so alleen is, ek het nie vriende nie of so nie." (Rosy)

"...it (AIDS) batters me it exhausts me, it feels like I shouldn't have friends. I shouldn't communicate with other people, I should just be with my two children...." (Hester)

"...dit (VIGS) takel dit my maak my gedaan, dit voel of ek nie moet vrinde het nie. Ek moet nie met ander mense kommunikeer nie, ek moet net met my twee kinders wees..." (Hester)

"To this day they (her family) don't know that I'm ill... Then I felt like being on my own, I went out of the house." (subject starts crying) (Mariana)

"Tot vandag toe weet hulle (haar familie) nie dat ek siek is nie... Dan het ek gevoel om op my eie te wees, ek het uit die huis uit gegaan." (subjek begin huil) (Mariana)

"Sometimes I just stare into the blue, then I just want to sit apart, sit alone and think." (Joeyce)

"Partykeer dan staar ek net in die bloute in, dan wil ek net eenkant sit, alleen sit en dink." (Joeyce)

"Elsa it has, when I heard heard it, it changed my life a lot. I probably don't I don't want to go out, I don't want to be outside, I don't want people… they know they don't know I have the sickness but to me it seems everybody knows I have the sickness and I don't want to be noticed." (Elna)

"Elsa dit het, toe ek dit gehoor gehoor het ek het dit, het my lewe baie verander. Ek wil nie seker ek wil nie uitgaan nie, ek wil nie buitekant is nie, ek wil nie mense… hulle weet hulle weet ek het nie die siek nie, maar vir my lyk dit almal weet ek het die siek en ek wil nie raakgesien wees nie." (Elna)

Several of the participants in a study conducted by Sandstrom (1993) came to view physical and social isolation as the best means available to them for escaping from both interpersonal difficulties and their own feelings of ambivalence. By withdrawing from virtually all interaction, they sought to be spared the social struggles and emotional tension that could be elicited by others' recognition of their condition.

Sylvie started distancing herself from her children by not making contact with them as she did before. For her this was a way of coping with the illness and the idea of leaving her children behind, should she die:

"More and more yes, more and more and I started keeping away more from my children… I um I don't want them so attached to me and and perhaps tomorrow or the next day they have to lose me just like that and and they must perhaps see how how I deteriorate." (Sylvie)

"Al hoe meer ja, al hoe meer en ek het meer begin te weg bly van my kinders af… ek um ek wil hulle nie so vas aan my hê nie en en miskien môre oormôre moet hulle my net so verloor en en hulle moet miskien sien hoe hoe dat ek agteruitgaan." (Sylvie)

The higher levels of psychological distress reported in the study by Katz et al. (2002) were related in part to the occurrence of recent stressful life events, a lack of perceived social support, and the women's use of avoidant coping as opposed to more effective emotion- or problem-focused ways of coping with their illness. In the present study, it was quite clear that the participants endured many stressors relating to family life and responsibilities and the lack of adequate emotional and social support. They used secrecy, concealment and social withdrawal to avoid stigmatisation and rejection from others, which most probably caused them further psychosocial distress and the probability of potential care/support.

Hester isolated herself emotionally and socially to such an extent that it had a detrimental effect on her physical health:

"Sometimes the clinic sisters even brought me my pills to the squatter camp as well. Because then I just feel I don't want to go out... but sometimes it feels to me I can go out of my mind from all the all the things they say like that about my name... I don't take it so seriously, but it hurts, it hurts very much... Then I don't want to do anything Elsa I just lay like that and lay until later on I wasted away and deteriorated. My parents searched for me, they didn't find me, because I wanted nobody near me." (Hester)

"Sommige tye het die kliniek susters selfs my pille in in plakkerskamp toe gebring ook. Want dan voel ek net ek wil nie uitkom nie... maar sommige kere dan voel dit vir my ek kan van my kop af raak van al die al die dinge wat hulle so praat van my naam... ek vat dit ek vat dit nie so ernstig op nie, maar dit maak seer, dit maak baie seer... Dan wil ek niks doen nie Elsa ek het net so gelê en gelê tot ek later van tyd uitgeteer en agteruit gegaan het. My ouers het na my gesoek, hulle het nie vir my gekry nie, want ek wou niemand naby my gehad het nie." (Hester)

Hudson et al. (2003) found that HIV-positive women were significantly less likely to ask for help with daily activities and family responsibilities and more likely to utilise avoidance behaviours to deal with their chronic illness, compared to HIV-negative women. Moneyham et al. (cited in Gaskins, 1991) found in their study that protecting their confidentiality even prohibited some women from using needed medical and social resources and services. Faithfull (1997) stated that although silence and withdrawal lead to isolation and a lack of support, it may also have a protective function, bolstering denial and preventing women from becoming fully aware of the painful consequences of being infected (Faithfull, 1997). Raganye (2003) found that emotion-focused strategies such as distancing had significant negative correlations with depression.

However, Gillman and Newman (1996) stated that keeping HIV/AIDS a secret precludes possible sources of support and acceptance. Pennebaker (cited in O'Leary & Helgeson, 1997) suggested that it is important to disclose, to some extent, feelings about stressful life events. He found that inhibition of affect and non-disclosure of personally distressing experiences produce negative health consequences and that disclosure produces positives ones. Hackl et al. (1997) stated that secrecy and non-disclosure may hinder a woman's ability to develop effective coping strategies and leave her vulnerable to fear, anger and depression. The obvious disadvantages of self-isolation and non-disclosure are that the

person simultaneously lessens any possibility of receiving emotional support or understanding from family, friends and the community. While such self-imposed isolation protects the person from adverse reactions, it also excludes supportive responses and can, therefore, contribute to further psychological distress such as prolonged or intensified experiences of loneliness, anxiety and depression (Kelly et al., 1988; Sandstrom, 1993).

For the participants in the present study silence and social withdrawal led to isolation and a lack of support, but it also served the purpose of protecting them against stigmatisation, scorn and judgement from others. From their citations it was quite clear that they were experiencing many distressing consequences of being HIV-infected, but to avoid further distress they chose to withdraw and isolate themselves. For the reason that these women generally experienced their illness and related stressful circumstances as uncontrollable, and thus could do little to change it, emotion-focused coping behaviour can be perceived as a likely and probably the only viable response. Furthermore, the construction of HIV/AIDS as an illness that is shameful and blameworthy, as well as an illness that is incapacitating, is incompatible with the construction of being a "good" woman. It can be suggested, then, that because women feel that they are not "making it" in terms of constructions of ideal womanhood, they respond by withdrawing and isolating themselves. This again shows that HIV/AIDS is a gendered construction, because women have a different illness experience than men.

5.6.2 Alcohol abuse

All the participants in the present study, except Nossie, used alcohol as a means of coping with their illness. Although Mariana denied during the interview that she used alcohol, the researcher was aware of her serious alcohol problem, through contact with the local welfare services regarding this problem and the care of her children. This was also the most important reason why the welfare services had placed her children in her mother's care.

After being informed of their HIV-positive status, many of the participants started using alcohol to cope with their illness condition:

"But after that message I got that I was positive, I took a beer last week, so it always comes back. It's almost like a craze that comes upon me. But it's really also an illness, once I start I can't stop myself..." (Maggie)

"Maar na daai boodskap wat ek gekry het dat ek positief is, het ek nou nog laas week 'n biertjie gevat, so dit kom altyd weer. Dis amper soos 'n gier wat by my op kom. Maar dis eintlik ook 'n kwaal, as ek een keer begin dan kan ek my nie stop nie..." (Maggie)

"In the beginning when we heard about the sickness it drove us to things, Elsa. Things that we shouldn't do... I didn't want to be around people any more, I started doing things in my life. I started drinking, things I didn't use to do." (Hester)

"In die begin toe ons gehoor het van die siek, het dit ons gedryf na dinge toe Elsa. Dinge wat ons nie moet doen nie... Ek wil nie meer rondom mense gewees het nie, ek het beginne dinge doen in my lewe. Ek het beginne drink, dinge wat ek nie gedoen het nie." (Hester)

"...and later on I started using alcohol, because I didn't know what to do... used alcohol and then I thought no I'm now getting sicker and sicker, rather leave the alcohol." (Rosy)

"...en later van tyd het ek beginne alkohol gebruik, want ek weet nou nie wat om te doen nie... alkohol gebruik en toe dink ek nee ek raak dan nou al sieker, los maar die alkohol." (Rosy)

As in many other research studies, Kimerling et al. (1999) found that the majority (72%) of the HIV-infected women in their study reported a history of alcohol abuse.

In the present study alcohol was used by most of the participants to ease emotional distress and to forget about their illness condition as well as to escape from daily stressors and worries:

"I think of it a lot, but sometimes I think I I don't want to think about it... I also take a drink and so, but not like my husband. Sometimes I just drink so much that I lie drunk. When I'm right again then I think again that it's wrong, I also don't want to do it. And I think think of the children... one feels at the time you just want to do something to forget and then I think it doesn't work like that." (Ann)

"Ek dink baie daaraan, maar somtyds dink ek ek wil nie daaraan dink nie... Ek drink ook 'n drankie en so, maar nie soos my man nie. Partykeer dan drink ek my sommer dat ek dronk lê. As ek weer reg is dan dink ek weer dit is verkeerd, ek wil dit ook nie doen nie. En ek dink dink aan die kinders... mens voel daai tyd jy wil net iets doen om te vergeet en dan dink ek dit werk nie so nie." (Ann)

"Then I was so upset that she (her sister) fought with me like that, then I went to the bottle again and I still take a beer now and then when I get so upset when they carry on like that in the house." (Elna)
"Toe is ek so ontsteld dat sy (haar suster) vir my so baklei, toe is ek alweer drankbottel toe en ek vat nou en dan 'n biertjie nog as ek so ontsteld is as hulle so aangaan in die huis." (Elna)

"Because I told him (boyfriend) I would like to leave the drink again, because I don't I don't want to belong to it, but I I I will just have to take a beer, because it's the only thing that helps me it just takes away my thoughts from the problems..." (Elna)
"Want ek het vir hom (mansvriend) gesê ek wil graag die drank weer los, want ek wil nie ek wil nie aan dit behoort nie, maar ek ek ek sal maar net moet 'n biertjie vat, want dis al wat my help dit haal my gedagte net van die probleme..." (Elna)

"... I um just feel I'm deteriorating, my children are deteriorating, because I uh drink too much perhaps and there is and um I alone have to work... I uh sometimes I'm just unhappy I'm just unhappy and then I'll sit and drink." (Sylvie)
"...ek um voel net ek raak agteruit, my kinders raak agteruit, want ek uh drink miskien te veel en daar is en um ek is alleen wat moet werk... Ek uh partykeers is ek net ongelukkig ek is net ongelukkig en en dan sal ek sit en drink." (Sylvie)

Maggie and Bertha narrated that they used alcohol when they felt lonely:
"Because look they're now drunk and they chat go dancing, and I... then I just sit there. I feel so withdrawn don't have company and so on. But one thing, if I've had a beer, I'm very peaceful." (Maggie)
"*Want kyk hulle is nou dronk en hulle gesels loop dans, en ek... dan sit ek maar net daar. Ek voel so terug het nie geselskap en so nie. Maar een ding as ek 'n bier gedrink het, is ek baie rustig." (Maggie)*

"I then just sit like that alone, then there's nobody. Then it's just me alone, then of course I just have a little drink by myself." (Bertha)
"Ek sal dan sit ek maar so alleen, dan is daar mos niemand nie. Dan is dit net ek alleen, dan drink ek mos sommer so 'n drinkie by my." (Bertha)

From the above narrations it seems that alcohol is also used as a strategy of withdrawal and disconnecting. In the study conducted by Hackl et al. (1997) the emotion-focused coping strategy of avoidance was characterised by using distracting, blocking or blunting techniques, such as drinking alcohol. In this study, as in the present study, the women participants used alcohol to cope with their loneliness and to forget about their distressing illness. Beake and Goosen (1996) stated that alcohol abuse in South Africa is particularly

problematic in communities where women are exposed to violence and unemployment and have many family caregiving responsibilities. According to these writers, women turn to substances to ease stressful living conditions. The participants in the present study were all disadvantaged women, the primary caretakers of children, living in communities where violence, unemployment and substance abuse were common phenomena. Consequently, they used alcohol to escape the distress caused by their illness as well as their stressful living conditions.

The negative consequences of alcohol use were clear in the participants' accounts. Certain participants in the present study reported verbal and physical fights with their partners, emotional and financial neglect of children, as well as bodily ailments:

"...but it's just sometimes when perhaps the devil is so troublesome and I take a little drink. Then P (boyfriend) and I fight, he hits me and I hit him. My child sees it and then I said to him we'll have to stop doing it." (Maggie)

"...maar is net partykeer as ek miskien die duiwel so lastig is en ek vat 'n drankie. Dan baklei ek en P (mansvriend), hy slaan vir my en ek slaan vir hom. My kind sien dit en toe sê ek vir hom ons sal moet ophou om dit te doen." (Maggie)

"I started drinking I drank seriously and he (her husband) started smoking dagga (marihuana). Carried on, he fought with me each time and... but we ended up at the welfare in Tygerberg Hospital." (Hester)

"*Ek het beginne drink ek het ernstig gedrink en hy (haar man) het beginne dagga rook. Tekere gegaan hy het elke tyd met my gebaklei en... maar ons het by die welsyn gekom by in Tygerberg Hospitaal." (Hester)*

"And so I also a little bit and a little bit (used alcohol) together with them and it got worse. Sometimes I just feel I have to stop here, my children are getting neglected, I'm getting neglected, I have nothing of my own my children have nothing... but how do I stop?" (Sylvie)

"En so het ek ook maar saam met hulle so bietjie en so bietjie (alkohol gebruik) en dit het erger geword. Partykeer dan voel ek maar hier moet ek ophou, my kinders verwaarloos, ek verwaarloos, ek het niks van myself nie my kinders het niks nie... maar hoe hou ek op?" (Sylvie)

McDonnell et al. (2003) reported that HIV-positive women in their study were more likely than HIV-negative women to report that they had been drinking or using drugs prior to or during the physical abuse perpetrated by an intimate partner.

Joeyce's citations show that she had a severe alcohol-abuse problem, which had a detrimental effect on her physical health:

"I drink weekends. I have felt since I got the stomach that when I drink wine, my stomach starts pulling into a knot. Then it cramps then I just have to sit so bent double… It has cramps and I just had constant diarrhoea." (Joeyce)

"Ek drink naweke. Ek het gevoel vandat ek die maag gekry het, as ek wyn drink dan begin my maag op 'n hoop te trek. Dan kramp dit dan moet ek net so sit inmekaar… Dit het krampe en my maag het net gewerk aanmekaar." (Joeyce)

"Now if I perhaps run into a friend there, then I say no man, a dumpy is too little, you throw in a rand then we drink a bottle for once. So, and now after that bottle they just keep coming one after the other… Now you drink on your empty stomach and that's why my stomach looks like that inside. Seems to me it was completely raw from just drinking." (Joeyce)

"Nou as ek miskien daar 'n vriend raak loop, dan sê ek naai man 'n dampie is te min, gooi jy rand in dan drink ons sommer een maal 'n bottel. So, en nou na daai bottel dan kom hulle sommer so aanmekaar… Nou drink jy op jou leë maag en dit dat my maag so binne lyk. Lyk my dit was heel rou gewees van net drink." (Joeyce)

"I've drunk myself sick at times so that I had gastro and almost died from that gastro. I have just every day that God gives, from the morning that I get up that I open my eyes then I don't even think of a cup of coffee or a cup of tea, I was gone. I just make sure that I have two rand for the next day. Then they now two rand for those dumpies those 500 dumpies, two rand and three rand for a bottle." (Joeyce)

"Ek het my al siek gedrink dat ek gastro gehad het en amper dood van daai gastro. Ek het sommer elke dag wat God gee, van die oggend wat ek opstaan wat my oë oopgaan dan dink ek eers nie om 'n koppie koffie of 'n koppie tee nie, ek is weg gewees. Ek sorg net dat ek 'n twee randjie het vir die next dag. Toe hulle nou twee rand vir daai dumpies daai 500 dumpies, twee rand en drie rand vir 'n bottel." (Joeyce)

Beake and Goosen (1996) stated that alcohol abuse or alcoholism can have devastating effects on women; it can affect mental and physical health, destroy relationships, cause chaos in the home environment, and create work and financial difficulties. According to these writers, the physical effects are severe, ranging from fertility problems, malnutrition, diseases of the heart and liver, to neurological illness conditions.

Many of the participants in the present study realised that alcohol was detrimental to their health and not a solution to their problems. They expressed a serious need for help and support to quit the habit:

"I don't know but I'll have to get myself something against it. Not to say that I drink, I want to, I would like to drink less, but the problem is if once I start with one then I go all out for it. After a time I drink so much that I, nobody can control me any more or so. Everybody drinks in that house and when I see drink then I feel like having it." (Maggie)

"Ek weet nie maar ek sal my iets moet kry daarteen. Nie om te sê ek drink, ek wil, ek wil graag minder drink, maar die probleem is as ek eers een begin het dan gaan ek uit vir hom. Na 'n tyd dan drink ek so dat ek, niemand my meer kan control nie of so. Almal drink in daai huis en as ek sien drank dan is ek lus daarvoor." (Maggie)

"I will get out of the habit slowly but surely, because I I I also tell him (boyfriend) I don't see that the drink is going to solve the problem. I'm still in the drink attitude, but I'm trying slowly and surely to get myself out of the habit and he should just give me a chance." (Maggie)

"Ek sal dit stadig maar verseker af leer, want ek ek ek sê ook vir hom (mansvriend) ek vat dit nie so dat die drank die probleem gaan oplos nie. Ek is nog in die drank houding, maar ek probeer maar stadig en verseker om dit vir myself af te leer en hy moet vir my net kans gee." (Maggie)

"And when I heard heard of the problem (HIV), then I was still just drinking normally the way I used to drink, a lot. Until I decided a short while ago the new year but it's not worth it, I'm now going to stop. And I stopped just like that (subject clicks her fingers), but now my problems are starting again. " (Elna)

"En toe ek gehoor gehoor het van die probleem (HIV), toe het ek maar steeds gewoonweg gedrink soos ek gedrink het, baie. Tot ek maar nou nou die nuwejaar besluit het maar dis nie die moeite werd nie, ek gaan nou ophou. En ek het net so opgehou (subjek klap haar vingers), maar nou begin my probleme alweer." (Elna)

"I thought later on I'm just making myself weak and I don't want to eat, I just want that wine. The food doesn't want to go in, but the wine goes in..." (Joeyce)

"Ek het later van tyd gedink ek maak net myself swak en ek wil nie eet nie, ek wil net daai wyn hê. Die kos wil nie in gaan nie, maar die wyn gat in..." (Joeyce)

"Then I just drink... and and I I feel I spend money on that. I also think to myself but it just breaks me down and it doesn't benefit me to (drink) so, but I just can't put a stop to it." (Sylvie)

"Dan drink ek maar... en en ek ek voel ek gee geld uit daarvoor. Ek dink ook by myself maar dit breek my net af en dit baat nie vir my nie om so, maar ek kan net nie 'n stop daaraan sit nie." (Sylvie)

Numerous studies have been published reporting the influence of substance abuse behaviours on women with HIV/AIDS (De Marco & Johnson, 2003). These studies suggested that women with HIV/AIDS using substances have lower independent functioning levels with regard to daily activities and lower overall quality of life. Vosvick et al. (2003) found in their study that greater use of self-distraction, escapism, behavioural disengagement and substance-use coping strategies was associated with less energy and poorer social functioning. Sowell et al. (1999) stated that there is also evidence of an association between depressive symptoms and certain behaviours that are linked with HIV illness progression, for instance, substance abuse, smoking and high-risk sexual practices. Bing et al. (cited in Bride & Real, 2003) stated that substance use among women with HIV/AIDS could have a negative effect on quality of life, utilising health services, adherence to medication regimens and health outcomes. In the present study participants used alcohol to withdraw and disconnect, to forget about their illness and worries and to escape daily stressors. The participants' narrations show that many of them abused alcohol on a regular basis. On a more positive note, most of them realised that they had a problem and wanted help to quit the habit.

Given the construction of HIV/AIDS as an illness that people should be ashamed of, and be blamed and rejected for, and consequently an illness that has to be suffered alone, it is understandable that coping strategies such as withdrawing, disconnecting and escaping become the norm for women such as the participants in the present study. It can be argued, then, that the lack of emotional and social support, in terms of coping resources, played a significant role in the prevalent use of emotion-focused coping that was found among the participants in this study.

5.6.3 Faith and prayer

The participants in the present study related some emotion-focused coping strategies that helped them to alleviate their distress caused by their illness condition. Many participants in the present study conveyed their faith in God and used prayer as a coping skill:

"When I sit so quietly alone then I talk so alone out of myself so alone. Then I think oh dear why should this be happening to me so on. God help and so on with my weak body. There's not even strength any more, give me strength." (Bertha)

"As ek so alleen stil sit, dan praat ek so alleen uit my eie uit so alleen. Dan dink ek ai hoekom moet dit dan met my gebeur so aan. Here help en so aan met my swak liggaam. Daar is nie eers meer krag nie, gee vir my krag." (Bertha)

"…I just prayed and asked the Lord, Lord, it's now like this we can do nothing against it, you then be powerful for us and make us strong that we should accept everything about the sickness." (Hester)

"…ek het net gebid en vir die Here gevra, Here dit is nou so ons kan niks maak nie daarteen nie, wees u dan vir ons kragtig en maak vir ons sterk dat ons alles moet aanvaar van die siek." (Hester)

"Or I hope the Lord will still take us further without the doctors' contribution or so. Then I think oh gosh the Lord is good of course, the Lord can indeed strengthen us up to that lifelong. These are the only things I'm thinking about now…" (Rosy)

"Of ek hoop die Here sal nog vir ons verder sien sonder die dokters se se bydrae of so. Dan dink ek ai jinne die Here is mos goed, die Here kan mos vir ons versterk tot daai lewenslank toe. Dit is al dinge wat ek nou oor dink…" (Rosy)

"… you look in the priest's eyes… he tells you the body and the blood that Jesus gave to you and you say amen and you put that communion in your mouth and you walk away from there and you sit down and you say your prayer… then you feel like a new person as you walk out of there. Back at home you're so joyful, that's what I am, what I feel." (Joeyce)

"…jy kyk in die priest se oë… hy sê vir jou die liggaam en bloed wat Jesus aan jou gegee het en jy sê amen en jy sit daai nagmaal in jou mond en jy stap daar weg en jy gaan sit en jy sê jou gebed op… dan voel jy soos 'n nuwe mens as jy daar uitstap. Weer by die huis kom is jy so vreugdevol, so is ek, voel ek." (Joeyce)

According to Gaskins (1999), women often use prayer as coping mechanism to deal with an HIV-diagnosis. Simoni and Ng (2000) stated that prayer and rediscovery of what is important in life tend to be the most prevalent coping responses for women with HIV/AIDS, followed by coping strategies such as seeking information or making plans. Kaplan et al. (1997) also found that prayer and personal rediscovery, namely finding new meaning in one's existence, were the most prevalent means of coping.

Certain participants prayed for the healing of their ill children:

"But I was just in tears it was just I just cried. The tears just ran of their own accord and I sat there with my child and I just stayed praying with the Lord. I asked the Lord I asked the Lord does the child now have (HIV), does she have to suffer like this? I asked him (God) to heal my child, he must lessen her suffering a bit. That pain she always gets in her stomach." (Nossie)

"Maar ek was net in trane dit was net ek het net gehuil. Die trane het net vanself geloop en ek het gesit daar by my kind en ek het net biddend gebly by die Here. Ek het vir die Here ek het vir die Here gevra het die kind dan nou (HIV), moet sy so ly? Ek het vir hom (die Here) gevra om my kind gesond te maak, hy moet vir haar bietjie hy moet vir haar afbring van die lyding. Daai pyn wat sy altyd op haar maag kry." (Nossie)

"And I took up my child, I took her to the church so that they must pray for her. Then sometimes I pray then I also ask the Lord, even if you don't heal me, can't you just keep my children healthy." (Hester)

"En ek het my kind opgevat, ek het haar na die kerk toe geneem dat hulle vir haar moet bid. Dan sommige tye dan bid ek dan vra ek ook vir die Here, al maak jy nie vir my gesond nie kan jy nie maar my kinders gesond hou nie." (Hester)

Nossie expressed her belief in an afterlife and this comforted her when she thought of her child dying:

"But in the evenings when I lie at home, then I think what is she doing (child in hospital). If I'm going to lose my child, then he talked (pastor) then he felt we were talking about death. If I'm going to lose my child, we are borrowed on earth. We are not here permanently on earth… Then I said to him uh uh uncle knows how I feel about my child, she's almost like my sister. I can't do without her. Now I told him if it happens, if it is the Lord's will, then then I must let it be done." (Nossie)

"Maar saans as ek by die huis lê, dan dink ek wat maak sy (kind in hospital). As ek my kind gaan verloor, toe praat hy (pastoor) toe voel hy ons praat oor die dood. As ek my kind gaan verloor, ons is geleen op die aarde. Ons is nie hier permanent op die aarde nie... Toe sê ek vir hom maar uh uh oom weet hoe ek voel oor my kind, sy is amper soos my suster. Ek kan nie sonder haar nie. Nou sê ek vir hom as dit gebeur, as dit die Here se wil is, dan dan moet ek dit laat geskied." (Nossie)

Withell (2000) stated that life with HIV/AIDS unavoidably involves loss and change, stigma and suffering, but in the face of the distress, it is possible for women to emerge with spiritual strength and a more positive and hopeful view of life. Relf (cited in Withell, 2000) stated that spirituality frequently increases in significance for HIV-infected women, and contemplation on the meaning of life can lead to spiritual enrichment. In a phenomenological study Coward (cited in Sarna et al., 1999) noted that women expressed

the themes of "having a purpose and making a difference" and of AIDS being an "opportunity". Therefore, spirituality (or religion) can play a more central role in the lives of HIV-positive women than generally expected. The deepening of their religion experienced by quite a few women in the present study emphasises the need for a holistic approach to healthcare that respects the importance of this area as a resource for HIV-infected women.

5.6.4 Hope

As has been mentioned previously in this document, at the time when the interviews were conducted with the participants in the present study, there was no antiretroviral medication available for them, because they were disadvantaged and poor, and solely dependent on state-provided healthcare. Nevertheless, many participants still expressed their earnest hope for a cure in the future, for themselves and their HIV-infected children:

"I just hope there will be an antidote against it some day as they've said. I also listen a lot to the news and the stories, things like that." (Maggie)

"Ek hoop maar eendag daar is 'n teenmiddel daarteen soos hulle gesê het. Ek luister ook baie nuus en die stories, dinge soos dit." (Maggie)

"I just hope um there will perhaps now be an an opportunity that we that the doctors perhaps can have a cure against the HIV. That I hope for very much..." (Rosy)

"Ek hoop maar nou net um daar sal seker 'n 'n geleentheid nou is dat ons dat die dokters miskien kan 'n cure het teen die HIV. Daarvoor hoop ek baie..." (Rosy)

"I'm just living to live out my life, but there are times that I just think um I a cure, they must just get a cure as soon as possible. That we can use it that we can get well." (Elna)

"Ek lewe maar net om my uit te lewe, maar daar is tye wat ek maar net dink um ek 'n cure , hulle moet net so gou as moontlik net 'n cure kry. Lat ons dit kan gebruik lat ons gesond kan word." (Elna)

"It's a sickness that can't be cured and even if it's a cure that just helps one a little bit, I would be very grateful the day I can get it for me and my small family, my boyfriend and my child. If I can get hold of it or can be used as a guinea pig, just to see where one can have a chance in life with the cure, I would be very happy to be able to use it." (Elna)

"Dit is 'n siek wat nie genees kan word nie en al is dit net 'n cure wat 'n mens nou 'n bietjie kan help, sal ek baie dankbaar wees as ek die dag dit kan kry vir my en my familietjie my kêrel en my kind. As ek dit kan kry in die hande kan kry of as proefkonyn kan gebruik word, net om te sien waar die mens 'n kans kan het in die lewe met die cure, dan sal ek baie gelukkig wees om dit te kan gebruik." (Elna)

"I hope that um that I'll stay healthy and that there would be medication to make me well. And that somewhere for my child also that the two of us together, that there is hope for the two of us together. That the two of us would go into the future together…that we are healthy. That we wouldn't think again of what had happened to us…" (Nossie)

"Ek hoop dat um dat ek um gesond sal bly en daar sal 'n medikasie wees vir my om my gesond te maak. En dat iewers vir my kind ook dat ons twee saam, dat daar hoop vir ons twee saam is. Dat ons twee saam die toekoms sal tegemoet gaan… dat ons gesond is. Dat ons nie weer sal dink aan dit wat gebeur het met ons nie…" (Nossie)

"…I would like to hear or perhaps on the TV something comes about AIDS and and the treatment that they perhaps, then I hope so much that… And I mean um I keep hoping that there is uh a thingummy (cure) even if it's not for myself, but for other people and for my children and uh families. That hope will always come or that there is something that can cure it perhaps in later years or that just prevents it from happening now." (Sylvie)

"…ek wil graag hoor of daar is miskien op die TV wat daar iets kom oor VIGS en en die behandeling wat hulle miskien, dan hoop ek so dat… En ek meen um ek bly hoop dat daar is uh 'n dinges is al is dit nie vir myself nie, maar vir ander mense en vir my kinders en uh families. Dat daar altyd hoop sal kom of daar iets is wat wat dit kan genees miskien later van jare of net verhoed dat dit nou nie gebeur nie." (Sylvie)

Although emotion-focused coping strategies of self-blaming, denial and wish-fulfilling fantasy were significantly linked to greater anxiety and depression in a clinic sample of HIV-positive women (Commerford et al., cited in Hough et al., 2003), some emotion-focused strategies, for instance self-control and hopefulness, were associated with low levels of distress (Pakenham et al., cited in Simoni & Ng, 2000).

For some of the participants in the present study, like Elna and Nossie, their children and the future of their children gave them hope and inspiration for a longer and meaningful life:

"But I feel my future ahead I want to see my child grow up, I want to bring her up myself, I want to see her grow up. I want to take her to school, I want to do everything for her. And we must just be together…" (Nossie)

"Maar ek voel my toekoms vorentoe ek wil my kind sien groot word, ek wil haar self groot maak, ek wil haar sien groot word. Ek wil haar skool toe neem, ek wil alles vir haar doen. En ons moet net bymekaar wees…" (Nossie)

"The first time when I got the news I felt but I rather want to be dead, but after that I said to myself, you have a child you have something to live for." (Elna)
"Eerste keer toe ek die nuus kry het ek gevoel maar ek wil liewer dood wees, maar daarna het ek gesê vir myself, jy het 'n kind jy het iets om voor te lewe." (Elna)

"… I would do anything to give her (her child) a life a life, while there's a chance to give it to her… And this is my desire I would like to take my child to school, I still want to be alive at that time to take her to school (subject laughs) and to see her grow up." (Elna)
"…ek sal wat wil doen om vir haar (haar kind) 'n lewe 'n lewe te gee, terwyl daar 'n kans is om dit vir haar te gee… En dit is my begeerte ek wil graag my kind skool toe neem, ek wil nog leef daai tyd om haar skool toe te neem (subjek lag) en vir haar sien groot word." (Elna)

"That my child must get well and can have a good future and can make me a grandmother (subject laughs). I still want to live to become a grandmother, it's my biggest… she (her daughter) must be able to make me a grandmother, but we must first be able to get well. This is what I want, she must be able to make me a grandmother and bring lots of grandchildren." (Elna)
"Dat my kind gesond moet word en 'n goeie toekoms kan het en vir my 'n ouma kan maak (subjek lag). Ek wil nog lewe om ouma te wees, dis my grootste… sy (haar dogter) moet my kan ouma maak, maar ons moet eers gesond kan raak. Dit wil ek graag hê sy moet vir my kan ouma maak en klomp kleinkinders bring." (Elna)

A number of research studies have found that the presence of dependent children can encourage a positive attitude to life and increase coping skills (Withell, 2000). According to Andrews et al. (cited in Withell, 2000), children decreased feelings of isolation, were catalysts for positive behaviour change and were an important reason for the mothers not "giving up" (p.236). Leenerts and Magilvy (2000) found that the women in their study expressed a desire to find meaning in living and making decisions about life while facing death. As the participants in the present study, they also hoped for a longer and more meaningful life for themselves and their children.

5.6.5 Other coping strategies

Additional coping strategies mentioned by some of the participants in the present study were socialising with friends, keeping busy by doing household tasks, reading, sleeping, and living healthily.

A few participants, like Mariana, mentioned that socialising with other people helped them to forget about their illness:

"They (her friends) are always with me, they chat about other things. When I'm on my own again, then I think of it… (subject starts crying). I go and sit with my friends so that I can just forget…" (Mariana)

"Hulle (haar vriende) is altyd by my, hulle gesels oor ander dinge. As ek weer allenig is dan dink ek daaraan…(subjek begin huil) Ek gaan sit by my vrinne dat ek net kan vergeet…" (Mariana)

For Sylvie, socialising meant keeping up a facade of being healthy and living a normal life. This made her feel accepted by people around her:

"…sometimes it's quite hard when you sit still. Then when you're among people I must again be someone else, who can laugh and talk and um can make a joke. And I think it's probably also that which keeps me more upright… even if I have the knowledge in me, but I try to live together with the people." (Sylvie)

"….partykeer is dit maar moeilik wanneer jy stil sit. Dan is dit nou wanneer jy tussen mense is moet ek my weer iemand anders wees, wat kan lag en praat en um kan 'n grap maak. En ek dink dit is seker ook dit wat my meer regop hou ek… al het ek die wete in my, maar ek probeer om te lewe saam met die mense." (Sylvie)

Hester related that just talking to a concerned friend and sharing household tasks made her feel better about herself and her illness condition:

"There's a woman she comes around, she says hello um Hester how are you this morning, how are you feeling, isn't there something I can do for you. Then she just makes then she makes me feel good Elsa, then then I say to her I'm going to do my washing now and take your washing as well then we'll go and wash it at the tap." (Hester)

"Daar is 'n vroutjie sy kom om, sy sê hallo um Hester hoe gaan dit vanoggend met jou, hoe voel jy, is daar niks wat ek vir jou kan doen nie. Dan laat sy my sommer dan laat sy my goed voel Elsa, dan dan sê ek vir haar ek gaan nou my wasgoed was en vat sommer jou wasgoed ook dan gaan was ons dit by die kraan." (Hester)

Ann and Rosy narrated that they kept themselves busy around the house to forget about their illness condition and worries:

"But like now, I'm at home and I think too much. I just want to keep busy, I just want to work and so on or be busy with something." (Ann)

"Maar soos nou, ek is by die huis en ek dink te veel. Ek wil net besig hou, ek wil net werk en so of besig wees met iets." (Ann)

"Yes, if I can just work then I forget about the sickness or about my worries. Then I forget then I'm just busy working or so..." (Rosy)

"Ja, nou net as ek kan werk dan vergeet ek van die siekte of van my bekommernisse. Dan vergeet ek dan is ek nou net besig om te werk of so..." (Rosy)

Other studies also found that HIV-infected women who kept themselves busy and involved in tasks coped more effectively with the illness than those who were more passive and unproductive (Berman, 1993). In the present study it was found that productivity was greatly influenced by the participant's physical condition and energy levels. Those participants with serious illness symptoms, who mostly complained of feeling constantly tired, were less able to perform household tasks and care for their families (see section 5.4.2.2 in this chapter). It can be argued, then, that because of the construction of AIDS as an illness that is incapacitating, by remaining active a person can escape the illness to a certain extent.

Reading and sleeping were also ways for Rosy to forget about her illness and daily problems:

"During the day I lie down then I read the newspaper or so just to take my thoughts away, problems, worries... but I sleep very much. When I've slept in the day, I also carry on sleeping in the evening." (Rosy)

"Deur die dag dan lê ek dan lees ek koerant of so om nou net die gedagte net weg te vat, probleme, worries... maar ek slaap verskriklik baie. As ek in die dag geslaap het, dan slaap ek in die aand ook aan." (Rosy)

Hester and Maggie narrated that they made an effort to live healthily, in order to strengthen their bodies and manage their illness in a more effective way. Hester said:

"I eat healthily I make sure that I always that I eat until I'm full… That's why HIV is important to me Elsa, I must things I must try to avoid things that can worsen the sickness for me. I must always think of good things, by eating healthily and living healthily…" (Hester)

"Ek eet gesond ek sorg dat ek altyd dat ek vir my vol eet… Dis waarom HIV is vir my belangrik Elsa, ek moet dinge ek moet goed dinge probeer vermy wat die siek vir my kan vererger. Ek moet altyd aan goeie dinge dink, deur gesond te eet en gesond gesond te lewe…" (Hester)

Maggie hoped that living healthily and maintaining a balanced diet could in the long run cure her of the illness:

"It has meant to me that I'm very sickly and it's a sickness one can't take away. There will be treatment given for it and if you persevere according to eating habits and such things and eat right then you would perhaps still um in course of time get to conquer it and in that way come out strong." (Maggie)

"Dit het vir my beteken dat ek baie sieklik is en dit is 'n siek wat mens nie kan weg neem nie. Daar sal behandeling daarvoor gegee word en as jy volgens eet gewoontes en sulke dinge vol hou en reg opreg eet dan sal jy miskien nog um mettertyd kry om dit te oorwin en so sterk uit kom." (Maggie)

Both Hester and Maggie also contemplated giving up bad habits, such as smoking and drinking, to improve their health:

"And I said to myself, Lord, Lord help me and deliver me from the illness, but because I know there's no deliverance and there is nobody that can cure me, I follow my own routine Elsa. I avoid drink I avoid serious smoking problems. I'm a smoker Elsa I smoke cigarettes, but I don't take it as seriously as I used it before… I try to avoid things, I don't want to drink I don't want to drink and land myself in drunkenness and things Elsa, because I know it's harmful to my body." (Hester)

"En ek het vir myself gesê, Here Here help my en verlos my van die siekte, maar omdat ek weet daar is nie verlossing nie en daar is nie niemand wat my kan genees maak nie, volg ek my eie roetine Elsa. Ek vermy drink ek vermy ernstige rook probleme. Ek is 'n roker Elsa ek rook sigarette, maar ek neem dit nie so ernstig soos ek dit voorheen gebruik het nie… Ek probeer dinge vermy, ek wil nie drink ek wil nie drink in dronkenskap en goete beland nie Elsa, want ek weet dit is nadelig vir my liggaam." (Hester)

"It's going to make me even weaker and therefore I need to have a lot of strength not to think of drinking. I must eat healthily, I must do exercises, I must believe and we must try in this way and so." (Maggie)

"Dit gaan my nog swakker maak en daarvoor moet ek baie krag het om nie daaraan te dink om te drink nie. Ek moet gesond eet, ek moet oefeninge doen, ek moet gelowig wees en ons moet so probeer en so." (Maggie)

Hester read books on HIV/AIDS and thereby gained knowledge about her illness, and most probably also gained information on how to manage her condition in a more effective way:

"I've often read books about HIV um persons and children and how they stand back. The long stories about them, I liked reading books about the illness. I'm very fond of reading books that deal with illness." (Hester)

"Ek het al baie kere boeke gelees van HIV um persone en kinders en hoe hulle terug staan. Die lang verhale van hulle, ek het graag boeke gelees oor die siekte. Ek is baie lief om boeke te lees wat siekte betref." (Hester)

Malcolm et al. (2003) found that patients, who were motivated to stay physically healthy and were good adherers to medical treatment, actively managed their moods through healthy lifestyles, medication and/or counselling. Hudson et al. (2003) stated that the number of distressful symptoms and symptoms of depression reported by the participants in their study were significantly linked with self-care activities. Reciprocally, depressive symptoms can negatively influence behaviours expected to promote and maintain health, including behaviours aimed at accessing and using HIV-related healthcare services. Thus, making an effort to live healthily can be a very positive and active coping mechanism.

For the participants in the present study, their faith in God, hope for a cure and living healthily were skills that helped them to cope better on an emotional and physical level with their illness. Coping skills like socialising, doing household tasks, reading and sleeping were mainly used by the participants to forget about their illness condition and to escape or avoid distressful thoughts regarding the consequences of being HIV-infected.

5.6.6 Summary

In the present study the participants used various coping strategies to manage and live with their illness condition. The coping strategies most often used by the participants were secrecy/concealment and social withdrawal, and the use of alcohol. The majority of the participants kept their diagnosis a secret, for fear of stigmatisation, rejection and abuse. All the participants in the present study, except Nossie, used alcohol to escape their

worries and problems, which had a harmful effect on their overall functioning, and on their physical and psychological health.

Other coping strategies used by the participants were faith and prayer, hope for a cure in the future for themselves and their HIV-infected children, and living healthily. The participants' children and the future of their children gave them hope and inspiration for a longer, fulfilling life. For some participants socialising with friends, keeping busy by doing household tasks, reading, and sleeping helped them to ease the stress caused by their illness condition and related problems. Most of the participants' coping behaviour can be interpreted as emotion-focused coping strategies, although some of these strategies, such as alcohol abuse, were more harmful than others. Although emotion-focused coping strategies eased their burdens in certain ways and also protected them from further distress, such as ostracism and rejection from others, it prevented them from dealing openly and effectively with real and essential issues.

A number of studies of coping within the context of HIV/AIDS have been reported in the literature. According to Lindegger and Wood (1995), Raganya (2003), Simoni and Ng (2000) and Sowell et al. (1999), a general finding is that individuals who are inclined to cope with their stressors in a more passive or emotional manner have higher levels of psychological distress than those who tend to utilise more active and problem-focused coping strategies. Raganya (2003) suggested from his research findings that the more HIV-positive women use coping strategies such as seeking social support, planful problem solving, and distancing, the lower their levels of depression tend to be. He also found that the more HIV-positive women tend to use emotion-focused coping strategies such as confrontive coping, self-control and escape-avoidance, the higher their levels of depression. Sowell et al. (1999) stated that emotion-focused coping strategies such as concealment and avoidance have been found to be associated with unfavourable consequences, such as higher levels of depression, greater anxiety, and inability to manage the illness. Fawzy et al. (cited in Sowell et al., 1999) found that both HIV-positive and –negative persons who reported greater use of avoidance coping also reported greater distress and feelings of anxiety than those who employed more active and problem-

focused coping strategies. Lesserman et al. (cited in Sowell et al, 1999) in addition reported that this style of coping led to greater depressive symptoms, anxiety, and lower self-esteem.

The above findings are comparable with data from other studies pointing to the use of problem-focused coping strategies as a significant predictor of quality of life (Swindells et al., cited in Hough et al., 2003), decreased psychological distress (Namir et al., cited in Hough et al., 2003), and fewer symptoms of depression (Fleishman et al., cited in Hough et al., 2003). In the literature it is clear that the use of emotion-focused coping strategies such as avoidance, withdrawal, concealment, and alcohol abuse were positively associated with more suffering, whereas the use of problem-focused strategies, such as spiritual activities, self-care and generally managing the illness, were negatively associated with physical and emotional distress.

The majority of the participants in the present study used emotion-focused coping strategies more frequently than strategies that were active and problem orientated. Consequently, their experience of extreme emotional and social isolation, their lack of support and care, as well as coping strategies such as escapism, caused them further psychological distress and pain. These psychological distresses identified during the interviews were anxiety and concerns regarding issues of life and death, which were concomitant with feelings of hopelessness and depression. It is suggested that within the dominant discourse of HIV/AIDS as a deadly and uncontrollable illness, an illness which is shameful and blameworthy, and and illness associated with secrecy, separation, suffering, loss, and loneliness, the participants experienced anxiety for not being able to cope with, or change their dreadful circumstances and destiny. The discourse of HIV/AIDS as an illness and the discourse of a “good” woman/mother and caregiver seem to be incompatible, because a “good” woman and caregiver is constructed as someone who is connected, physically strong, healthy and productive, someone who should be able to cope with her caregiving responsibilities despite difficult circumstances or other stressors. These anxieties and concerns regarding issues of life and death will be discussed in the following section.

5.7 Anxiety and concerns regarding issues of life and death

Throughout the qualitative interviews it was clear that the participants experienced anxiety relating to several stressors in their lives, inter alia, their illness and the management of their illness condition, stigmatisation and disclosure, the care of their children and partners, personal and social losses, and the lack of psychosocial support. In addition to these anxiety stressors, many fears and uncertainties were also expressed by the participants regarding the fatality of their illness condition, their survival and unsure future, death and suffering, which caused them to feel extremely anxious and distressed.

5.7.1 Duration of life, survival and future

The participants in the present study narrated many fears and uncertainties regarding their lifespan, survival and future. Most of them were anxious about their future, not knowing how long they would live:

"And how long like... oh well, I'm just living from day to day anyway, how long am I still going to live... because I keep thinking but how long I'm still going to live, I'm healthy today but tomorrow or the next day I can just be gone... And I'm always thinking of that and now even more um, how long do I still have to live, how long can I still carry on like this. It's very hard for me, I don't know, many times I feel like I have always been scared, I have to say, or I also don't really know if I'm scared of death. " (Sylvie)

"En hoe lank soos... ag ek lewe tog maar van dag tot dag, hoe lank gaan ek nog lewe... want ek bly dink tog maar hoe lank gaan ek nog lewe, ek is vandag gesond môre oormôre kan ek net weg wees... En maar ek dink altyd daaraan en nou nog meer um, hoe lank het ek nog om te lewe, hoe lank kan ek nog so aangaan. Dit is vir my baie moeilik ek weet nie, baie keer dan voel ek nogal soos ek was nog altyd bang moet ek sê of ek weet ook nie eintlik of ek bang is vir die dood nie..." (Sylvie)

"She (clinic sister) told me it's an illness that lets you live for ten years or twenty years or you don't know yourself how long you're still going to live." (Ann)

"Sy (kliniek suster) het vir my gesê dit is 'n siekte wat vir jou vir tien jaar of twintig jaar laat lewe of jy weet self nie hoe lank jy nog gaan lewe nie." (Ann)

"Yes Elsa, I always think inside me, our future while we're now still living together, we don't know what still lies ahead for us and we're already going through such very painful things. It scares me, Elsa." (Hester)
"Ja Elsa ek dink nog altyd in my in, ons toekoms wat ons nou nog saam lewe, ons weet nie wat nog vir ons voorlê nie en ons gaan nou al sulke baie pynlike dinge deur. Dit maak my bang Elsa." (Hester)

"For me... I know there, the future is to me still very, but I'm not sure of it, where it's going." (Maggie)
"Vir my... ek weet daar, die toekoms is nog vir my baie, maar ek is nie seker daarvan nie, waarnatoe nie." (Maggie)

"... be a cure. Then I said perhaps there won't be, because I don't know when I'm going to die..." (Rosy)
"...'n cure wees. Toe sê ek miskien sal daar nie, want ek weet nie wanneer gaan ek sterwe nie..." (Rosy)

The majority of the participants in the present study expressed their concerns regarding the treatment of their illness and recovery. Many of them, like Maggie, felt anxious about the possibility of dying before a cure was found for HIV/AIDS:

"I decided once and for all it is now like this and I can't do otherwise, there is no medicine and will perhaps still come some day, but perhaps it's too late." (Maggie)
"Ek maar een keer besluit dit is nou so en ek kan nie anders nie, daar is nie medisyne nie en sal miskien nog eendag kom, maar miskien is dit te laat." (Maggie)

Elna, like many other participants, feared that she and her HIV-infected child would die before a cure is found for their illness:

"I'm mostly afraid that I will die before the cure is there. I still want to be alive when the cure is there, that I can get well... I'm scared I won't be there that day and that the cure would be ready after that time. So it must rather be before the time, because I would like my child to get well." (Elna)
"Ek is die bangste lat ek gaan weg val voor die cure daar gaan wees. Ek wil nog lewe as die cure daar is, dat ek kan gesond word... ek is bang ek is nie meer die dag daar nie en dat die cure na daai tyd sal reg is. So dit moet eider voor die tyd, want ek wil graag hê my kind moet gesond word." (Elna)

As in the present study, fears and uncertainties regarding their own premature death and their children's futures were common amongst HIV-infected low-income women in various other studies (Heath & Rodway, 1999; Leenerts & Magilvy, 2000). According to these writers women must admit the possibility of their own death, while planning for the welfare of their children.

The majority of the participants in the present study expressed their earnest concern for their children's future welfare should they as primary caretakers fall ill or die:

"Uh it's my children, it's what will become of them. I don't know where they are going to land one day, if I'm no longer there, who will really care about them? I won't be there to be able to give them what they what I really want to give them..." (Sylvie)

"Uh dit is my kinders, dit is is wat word van hulle. Ek weet nie waar hulle eendag beland nie, as ek nie meer daar is nie wie sal vir hulle regtig omgee? Ek sal nie daar wees om vir hulle te kan gee wat hulle wat ek regtig vir hulle wil gee nie..." (Sylvie)

"I just think of my children who have to stay behind. I don't have a mother any more. My mother would have looked after them, there is no longer a grandmother..." (Ann)

"Ek dink maar aan my kinders wat moet agterbly. Ek het nie meer 'n ma nie. My ma sou omgesien het na hulle, maar daar is nie meer 'n ouma nie..." (Ann)

"That I would die and my child is perhaps still alive perhaps, understand Elsa. What's going to happen to my child if I'm not there...?" (Nossie)

"Dat ek sou dood gaan en my kind is dalk nog lewe dalk nog, verstaan Elsa. Wat gaan gebeur met my kind as ek nie daar is nie...?" (Nossie)

"I'm scared when I die what will become of my children. Will they be treated harshly. The one is already so or are people going to look after them... How are they going to grow up without a mother, if the mother is no longer there?" (Mariana)

"Ek is bang as ek dood gaan wat gaan van my kinders word. Gaan hulle stief gebehandel word. Die een is al klaar so of gaan mense na hulle omsien... Hoe gaan hulle groot raak sonder 'n ma, as die ma nie meer daar is nie...?" (Mariana)

"To think um when I'm not there any more and who is then going to look after my child and after my mother (subject cries)... Because I care very much for him (her child)... and then my my mother has to look after him alone and his dad who worked for him is in prison." (Sonja)

"Om te dink um as ek nie meer daar is nie en wie gaan dan vir my kind sorg en vir my ma (subjek huil)... Omdat ek vir hom (haar kind) baie omgee... en dan my my ma moet alleen vir hom sorg en sy pa wat vir hom gewerk het, is in die gevangenis." (Sonja)

Many participants were particularly worried about their very young children being left behind. Joeyce and Maggie expressed their hope to live long enough to see their young children grow up and become more independent:

"I just thought of my child, how how long still, how long am I still am I still going to live. To think I have a small child (subject cries) that I still have to see grow up... When I look at her sometimes and she's playing there on the veranda, then I think my child if you just had to know I'm going to leave you one of these days..." (Joeyce)

"Ek net gedink om my kind, hoe lank hoe lank nog, hoe lank gaan ek nog gaan ek nog lewe. Om te dink ek het 'n klein kind (subjek huil) wat ek nog moet sien groot raak... As ek haar partykeerse so kyk en sy speel daar op die stoep, dan dink ek my kind as jy net moet weet ek gaan jou een van die dae nog verlaat..." (Joeyce)

"And the, the only thing that bothers me I would just have wanted my child to be a big, a big man already so that he can stand on his own two legs. I just hope he would be big, sensible the day I'm perhaps not there any more." (Maggie)

"En die, die enigste wat my pla is ek wil net hê my kind moet 'n groot, 'n groot man al wees al, dat hy op sy eie twee bene kan staan. Ek hoop maar hy sal maar groot wees, verstandig wees die dag wanneer ek miskien nie meer daar is nie." (Maggie)

Rosy was so concerned about her young HIV-infected daughter, with whom she had a very close bond, that she contemplated that the child should rather die before her and not be left behind:

"I feel very bad, now I'm thinking she's so small and so. And I always wished for a girl child and this makes me sad sometimes... My biggest worries are um, now I think gosh now perhaps I get terribly ill and so. Now my children, how would my children be and so. Now I'm just thinking of the little one, then I think into the future, the Lord should perhaps first take her away and then me, because what is she going to do alone here. And we love each other so much, that's what I think of..." (Rosy)

"Ek voel baie sleg, nou dink ek sy is so klein en so. En ek het altyd verlang na 'n meisiekind en 'n dit maak my somtyds hartseer... My grootste worries is um, nou dink ek ai nou raak ek miskien vreeslik siek en so. Nou my kinders, hoe gaan my kinders nou is en so. Nou dink ek net om die kleintjie nou, dan dink ek ai in die toekoms in, die Here moet maar eers vir haar miskien weg vat en dan vir my, want wat gaan sy nou maak alleen hier. En ons is so lief vir mekaar, daaraan dink ek..." (Rosy)

Many other studies done on HIV-infected women with children also found that the well-being and care of their children was one of the most serious concerns for them, which led to feelings of anxiety and distress. According to Sowell et al. (1999), recent research indicated that women with HIV/AIDS are extremely worried about the impact of their illness on the well-being of their children, and many of their coping efforts are focused on their concerns regarding the care of their children should they fall ill or die. Kaleeba (cited

in Withell, 2000) confirmed that anxiety about children and their future care appears to be universal for all HIV-positive mothers, regardless of race.

From the above citations it seems that the participants' construction of HIV/AIDS as an incurable and deadly illness was conflicting with their construction of motherhood, of being the primary caregivers of children, because should they fall ill or die they would desert their children and thus fail as mothers.

5.7.2 Death and suffering

Many of the participants in the present study narrated that the thought of dying made them anxious:

"I'm also scared of dying... I'm very scared of dying (subject laughs softly), it's the most important..." (Joeyce)

"Ek is bang ook om dood te gaan... Ek is baie bang om dood te gaan (subjek lag sag), dit is die vernaamste..." (Joeyce)

"Because I don't want I I won't say I'm scared, but in a way I'm scared of being taken away from life. Because I'm still looking forward to it, I have a lot to live for." (Elna)

"Want ek wil nie ek ek sal nie sê ek is bang nie, maar op 'n way is ek bang om uit die lewe weg geneem te word. Want ek sien nog uit daarna ek het baie om voor te lewe." (Elna)

Other participants expressed their fear of pain and agony before they die as well as many uncertainties they had relating to the process of dying:

"I'm thinking now how am I going to die. Or, if I first before my husband, or what's going to happen. I think many things...Then I just think, will I have an illness or do I die in the hospital or so. Just to think of it every day... to think of death and so and of the children and so. When there is perhaps a serious illness, somebody perhaps becomes seriously ill, so... I think of it." (Ann)

"Ek dink nou hoe gaan ek die dag dood. Of, as ek eerste voor my man, of wat gaan gebeur. Ek dink baie dinge... Dan dink ek net, gaan ek 'n siekte het of gaan ek in die hospitaal dood of so. Net om daaraan te dink elke dag... om te dink aan die dood en so en aan die kinders en so. Die is daar 'n ernstige siekte miskien nou, iemand word miskien ernstig siek, so... ek dink daaraan." (Ann)

"What I'm most scared of (subject laughs nervously). I would say that what scares me most of all about HIV, I'm just scared that I would get sick quickly and I die. And that I'm going to suffer heavily after getting sick and that I would lie weak forever. That I won't be able to do anything for myself any more. That's what I'm scared of..." (Maggie)

"Waarvoor ek die bangste is (subjek lag senuweeagtig). Ek sal maar sê, waarvoor ek die bangste vir alles is van HIV is, ek is net bang dat ek gou gaan siek raak en ek gaan dood. En dat ek swaar en na daai siek raak gaan ly en dat ek sommer vir altyd gaan pap lê. Dat ek niks meer vir my kan doen nie. Dit is waarvoor ek bang is..." (Maggie)

"...the only thing I can think of um that I um perhaps uh I would I would lie and waste away perhaps the day I can no longer. Yes, how I'm going to suffer... I don't look like the person I used to look like... I die perhaps or I become I land in a hospital... The suffering I have to suffer, but it's hard for me to think that I have I have to suffer from an illness and I can become sick and I can die." (Sylvie)

"...al wat ek oor dink ook nog um dat ek um miskien uh ek sal ek sal lê en verteer miskien as ek die dag nie meer kan nie. Ja, hoedat ek gaan ly... Ek lyk nie soos die mens wat ek gelyk het nie... ek gaan miskien dood of ek raak in beland in 'n hospitaal in... Die lyding wat ek moet ly, maar dit is vir my swaar om te dink dat ek moet ek moet aan 'n siekte ly en ek kan siek word en en ek kan dood gaan." (Sylvie)

As in the present study, Leenerts and Magilvy (2000) found that uncertainties about what death would be like, and fears about pain and suffering, were deep concerns revealed by all the HIV-infected women participants in their study. According to Bee (1994) fear of death is in part the losses of experience, sensation, and relationships that people fear, but it may also include fear of the pain, suffering or indignity that may be involved in the process of dying itself. She stated further that this entails fear that one would not be able to cope with such pain or suffering, fear of whatever punishment may come after death, and an underlying fear of loss of self.

As has been mentioned before in this chapter, the women participants in the present study had no prospects of receiving treatment for their illness condition, because they were solely dependent on state health facilities that did not provide ART to state patients at that point in time. Given the construction of HIV/AIDS within their community as an incurable illness that ultimately leads to death, women with HIV/AIDS will understandably experience intense fears regarding suffering and the dying process.

5.7.3 Summary

In this section the discourse of HIV/AIDS was again prominent in the participants' accounts of their illness experience: HIV/AIDS is constructed as an incurable and deadly illness; an illness of shame and separation; and an illness associated with extreme suffering, pain, and loss.

It is clear from the above citations that the participants in the present study were extremely anxious and distressed regarding their illness condition, their future, and issues of life and death. They were anxious about how long they had to live, what the future held for them, how they would die, the illnesses and suffering accompanying the dying process, and death itself. The participants expressed fear for the unknown concerning dying and death, but did not explicitly share their feelings and thoughts about life after death. The researcher experienced most of the participants as Christian believers, who most probably believed in a life after death.

Nevertheless, the participants dreaded their future, because it entailed many losses and an early death. Charmaz (1997) explained that for ill people to exist in a dreaded future, they live in silent terror and wait for that future they know will come. Meanwhile, they study each developing symptom, each possible sign foreshadowing the dreaded future, the certain fate of dying (Charmaz, 1997). According to Charmaz (1997), feeling trapped by an uncontrollable future also traps the ill person in a state of negative emotions. Anger, self-pity, hopelessness and depression lead to and strengthen the feeling of being trapped, and vice versa.

The dominant discourse identified in the participants' accounts of their illness experiences was a discourse of HIV/AIDS as an incurable and deadly illness; an illness of shame; an illness of secrecy and silence; an illness associated with separation, losses, and loneliness; and an illness of pain and suffering. The above discourse operated concurrently with a discourse on motherhood and what it meant to be a "good" woman/mother: someone who is connected, physically strong, healthy and productive, and someone who is able to cope

with her caregiving responsibilities. It is argued, then, that the anxieties and fears experienced by the women in the present study about their future lives and early death, their deep concerns about not being able to be a “good” woman and mother, and their dilemma of not being able to change their circumstances and destiny, led to feelings of intense hopelessness, despair, and sadness. The participants’ experiences of hopelessness, despair, and sadness will be discussed in the following section on depression.

5.8 Depression

The psychological distress experienced by the participants in the present study, such as extreme loneliness, anxieties, fears and uncertainties, were in many instances simultaneously expressed with depressive feelings and were most probably indicators of depression.

According to the Diagnostic and Statistical Manual of Mental Disorders (1994), the two major symptoms of depression are a depressed mood (e.g. feels sad or empty) and loss of interest or pleasure in daily activities. Additional symptoms are weight loss or weight gain, insomnia or hypersomnia, psychomotor agitation or retardation (restlessness or being slowed down), fatigue or loss of energy, feelings of worthlessness or inappropriate guilt, diminished ability to think or concentrate, and recurrent thoughts of death and suicidal ideation.

In the literature it is stated that it is problematic to assess depression in people who are physically ill, including people who are HIV-infected. Raganya (2003) explained that one has to differentiate between depression which is due to psychological stress or adjustment stress, and depression which is a direct manifestation of the physical illness. He stated further that the overlap between depressive symptoms and physical and cognitive manifestations of symptomatic HIV complicates the issue of depression in HIV-infected people. According to Maj (1997), it is problematic to identify the boundary between

demoralisation as a result of depression and physical or clinical depression in HIV-infected individuals.

Certain writers recommended that the diagnostic criteria for depression that use the four psychological symptoms, which are tearful or depressed appearance, social withdrawal or not communicating, brooding or pessimism, and non-reactive mood, should be applied when assessing people with physical illnesses such as HIV/AIDS (Creed, 1997; Raganya, 2003). The latter is recommended instead of using the four somatic symptoms, which are weight change, sleep disturbance, fatigue and diminished concentration, because these symptoms may be the direct results of the physical illness rather than depression (Creed, 1997). For the present study the researcher decided to include and present psychological and neuro-vegetative symptoms of depression as narrated by the participants, because of the possibility that somatic symptoms were caused by a depressed mood. Furthermore, certain symptoms could have been caused by psychological and adjustment distress as well as the manifestation of the physical illness.

5.8.1 Sadness, hopelessness and despair

The participants in the present study narrated various symptoms of depression during the in-depth interviews. These symptoms were experienced from the time of diagnosis, as discussed in section 5.1 of this chapter. Feelings of intense sadness and despair were conveyed by all the participants:

"If I think of this, then then I just want to lie down… because it's sad it's… but I I can cry, but I can't cry away the pain, the sadness and the illness. Because that's something that's going to be with me always. It is, it's very deep inside of me…" (Maggie)

"As ek so daaraan dink nê dan dan wil ek sommer lê… want dit is hartseer dis… maar ek, ek kan maar huil, maar ek kan nie die pyn, die hartseer en die siekte kan ek nie weg huil nie. Want dit is iets wat vir altyd by my gaan wees. Dit is, dit is baie diep in my in." (Maggie)

"…it feels to me that sometimes I think gosh I'm going to get well, but then the very next day then I again feel so down and so depressed, like one who just wants to cry. Then I think it's the sickness that's doing it Elsa or what is it that makes me so powerless." (Hester)

"...sommige tye dink dan voel ek jinne ek gaan gesond raak, maar dan net die next dag weer dan voel ek weer so af en so teneergedruk net soos een wat net wil huil. Dan dink ek is dit die siekte wat dit doen Elsa of wat is dit wat my so kragteloos maak." (Hester)

"The sickness has it always seems as if lays something heavy on me, in my mind Elsa, I just don't feel or or I don't feel, when other girls when when they sit and chat, like going and sitting down with them also, to join them and chat." (Hester)

"Die siek het dit lyk altyd dit lê iets swaar op my, in my gemoed in Elsa, ek voel net nie of of ek voel nie soos ander meisie as as hulle nou lekker sit en gesels om ook daar by hulle te kom sit, aansluit en gesels nie." (Hester)

Hopelessness, like sadness, was a strong emotion that all the participants in the present study experienced, from the time of their diagnosis until the time of the interviews:

"But I knew they say it's an illness they can't cure... I thought now I'm going to die, because I I heard it's it's a serious illness, very serious illness, because they can't cure it. So I'm going to lose my child and then I'm also going to die." (Nossie)

"Maar ek het geweet hulle sê dit is 'n siekte wat hulle nie kan genees nie... Ek het gedink nou gaan ek dood, want ek ek het gehoor dit is dis 'n kwaai siekte, baie kwaai siekte, want hulle kan dit nie genees nie. So ek gaan my kind verloor en dan gaan ek ook dood." (Nossie)

"Because I know it's a sickness that nobody wants Elsa and that will never be cured... And I've said to myself, Lord Lord help me and deliver me from the illness, but because I know there's no deliverance and there's nobody who can cure me..." (Hester)

"Want ek weet dit is 'n siek wat niemand wil hê nie Elsa en wat nooit sal gesond raak nie... En ek het vir myself gesê, Here Here help my en verlos my van die siekte, maar omdat ek weet daar is nie 'n verlossing nie en daar is nie niemand wat my kan genees nie..." (Hester)

"It's useless to hope, I cannot get cured sister... Because there's not yet a medicine for the sickness... I pray for this day and night... It makes me feel bad, because there isn't a result... It seems as if it's never going to happen... That I can't get rid of the sickness... that I won't live long." (subject cries) (Mariana)

"Dit baat nie ek hoop nie, ek kan nie gesond raak nie suster... Omdat hier nog nie 'n middel is vir die siek nie... Ek bid dag en nag daarvoor... Dit laat my sleg voel, want daar is nie 'n uitwerking nie... Dit lyk so dit gaan nooit gebeur nie... Dat ek van die siek ontslae kan raak nie... dat ek nie lank sal lewe nie." (subjek huil) (Mariana)

"I almost feel like an outcast. Now I'm thinking of it that I'm sickly and there's something wrong with me that nobody can cure for me any more and not even God. There's no medication that has been prescribed for me..." (Maggie)

"Ek voel amper soos 'n verstoteling. Nou dink ek daaraan ek is sieklik en ek makeer iets wat niemand meer vir my kan genees nie en nie eers God nie. Daar is nie medikasie wat vir my voorgeskryf is nie..." (Maggie)

"And I'm always thinking of that and now even more um, how long do I still have to live, how long can I still carry on like this. That's how I feel sometimes, but I must just give up, just let go of everything, because everything is so in vain." (Sylvie)

"En maar ek dink altyd daaraan en nou nog meer um, hoe lank het ek nog om te lewe, hoe lank kan ek nog so aangaan. Dis soos hoe ek partykeer voel, maar ek moet net tou opgee net alles laat los, want alles is so verniet." (Sylvie)

In the literature, depressive symptoms are one of the most common distress responses reported by HIV-infected women. Kaplan et al. (1997) examined the prevalence of psychological distress in women diagnosed with HIV/AIDS in the United States. Of the women in their sample, 38% screened positive for a depressive disorder and 43% for an anxiety disorder.

According to many writers, depressive feelings, sadness, hopelessness and despair are often the first responses that are likely to occur after an HIV-diagnosis, which can develop into a more serious depressive condition as the illness progresses. Richardson et al. (2001) referred to several studies which suggest that depression is related to progressive disease, number of symptoms, and prior depressive episodes. Even though there is a strong correlation between depression and disease progression, Murphy et al. (2002) found that the majority of the asymptomatic low-income HIV-positive mothers in their study experienced symptoms of depression.

Because there were no future prospects for Sylvie, she felt unhappy most of the time and also experienced regular mood swings:

"To tell the truth I don't know I can't even think if I can still talk of a life I still have or what kind of life do I have? I'm just somebody who goes on from day to day and and... um and beyond that I don't live... I'm just unhappy the whole time. I feel the whole time just um... I'm alone and I um... so as if now I'm at peace and

um tomorrow or the day after then I have a mood over me that I don't understand myself... I also go off like someone who gets rebellious and so on. And um I used to be quite uh a calm person..." (Sylvie)

"*Om die waarheid te sê ek weet nie ek kan nie eers dink nie of ek nog kan ooit praat oor 'n lewe wat ek nog het nie, of watse lewe het ek? Ek is net iemand wat aangaan van dag tot dag en en... um en verder lewe ek nie... ek is die heeltyd maar net ongelukkig. Ek voel die heeltyd maar net um... ek is alleen en ek um... nou nou is ek tevrede en um môre oormôre dan het ek 'n buie oor my wat ek wat ek self nie verstaan nie... Ek raak ook af soos iemand wat opstandig raak en so aan. En um ek was maar uh 'n rustige mens..." (Sylvie)*

Rosy and Maggie, like many other participants, expressed their difficulty with the acceptance of their illness condition:

"Sometimes I just feel goodness me, as I've now said already, I feel why do I now have this and... and my child and my husband... Now I feel like the doctors have said already, um there's no um they can't help at all. Now I think oh gosh can't they make a plan... with the HIV. Why did it then have to come into existence and that's how I think..." (Rosy)

"Somtyds dan voel ek nou net ai jinne, soos ek nou al reeds gesê het, ek voel hoekom het ek dan nou dit en... en my kind en my man... Nou voel ek nou so soos die dokters mos alreeds gesê het um daar's nie um hulle kan niks help nie. Nou dink ek ai jinne kan hulle dan nie 'n plan maak nie... met die HIV nie. Hoekom moet dit dan ontstaan en so dink ek..." (Rosy)

"So I would rather say, the hardest of all for me is to accept it that I have HIV. It has meant to me that I'm very sickly and it's a sickness that one can't take away." (Maggie)

"*So ek sal maar eider sê, die moeilikste van alles is vir my om dit te aanvaar dat ek HIV het. Dit het vir my beteken dat ek baie sieklik is en dit is 'n siek wat mens nie kan weg neem nie" (Maggie)*

The predictable experiences of a terminally ill patient proposed by Kübler-Ross are shock, denial, anger, bargaining, depression, and acceptance as final stage (Torres, cited in Sherr, 1995). Sherr et al. (cited in Hackl et al., 1997) stated that anger and frustration about future goals and mourning for the loss of a long life were identified as common bereavement issues among HIV-infected women. It is clear from the above citations that the participants in the present study were not at the acceptance stage of their illness, but still struggling with distressful emotions such as hopelessness, despair and sadness.

5.8.2 Neuro-vegetative symptoms

The participants in the present study experienced and expressed depressive symptoms in bodily terms through several somatic symptoms. Some of the participants mentioned sleeping problems such as insomnia:

"I just keep myself occupied and so. It's really when I'm alone, when one sits like that and thinks of a thing. When I can't sleep at night, then one thinks of such things … I'm thinking now of how I'm going to die." (Ann)

"Ek hou my maar besig en so. Dit is eintlik wanneer ek alleen is, wanneer mens so sit en dink aan 'n ding. Wanneer ek nie kan slaap in die nag nie, dan dink mens mos aan sulke dinge… Ek dink nou hoe gaan ek die dag dood." (Ann)

"I'm strong, but I still always remember it is so, it is so… I just know it stays like this I can't do anything about it. Some of the nights are sleepless…" (Maggie)

"Ek is sterk, maar ek onthou nog altyd dit is so, dit is so… Ek weet maar net dit bly so ek kan niks daaraan doen nie. Van die nagte is slapeloos…" (Maggie)

"…I don't go around like before, I can no longer sleep some evenings, I'm restless…" (Maggie)

"…ek loop nie meer so in die rondte soos eers nie, ek kan nie meer party aande slaap nie, ek is rusteloos…" (Maggie)

"Not normal, because when I I never sleep through the night in any case. When W (her baby daughter) is at home… then my day of W starts … And when she sleeps in the evening it's again washing that I fold, things to iron, it's always until I go to sleep. But it's not sleep sleep…" (Nossie)

"Nie normaal nie, want as ek ek slaap nooit elk geval deur die nag nie. As W (haar baba dogter) by die huis is… dan begin my dag van W… En as sy in die aand slaap is dit weer wasgoed wat ek opvou, stryk goed dit is altyd tot ek gaan gaan slaap. Maar dit is nie slaap slaap nie…" (Nossie)

Bertha and Rosy were the two participants who experienced hypersomnia:

"Some mornings I lie in bed, then I sleep very long, easily around twelve hours. Then he (her son) dresses himself and then he washes himself. Then I sleep for long, I feel tired man… I've hardly watched TV then I'm gone… gone, then I don't know when the people fight outside. I'm gone gone gone… Then they have to wake me themselves, then I say no get out of here, then I sleep… I feel tired…" (Bertha)

"Soggens party soggende dan lê ek, dan slaap ek baie lank sommer hier twaalf uur. Dan trek hy (haar seun) vir homself aan en dan was hy vir hom. Dan slaap ek lank, ek voel moeg man… Ek het nog nie reg TV gekyk nie dan is ek weg… weg, dan weet ek nie wanneer baklei die mense hier buitekant. Ek is weg weg weg…

Dan moet hulle self vir my wakker maak, dan sê ek nee gaan hier uit, dan slaap ek… Ek voel moeg…" (Bertha)

"… but I sleep very much. When I've slept in the day then I carry on sleeping into the evening." (Rosy)
"…maar ek slaap verskriklik baie. As ek in die dag geslaap het, dan slaap ek in die aand ook aan." (Rosy)

The majority of the participants in the present study complained of weight loss (see section 5.3.1 of this chapter). Some of them reported that they generally tried to eat an adequate amount of healthy foods, even if their appetite was low. Maggie narrated a decrease in appetite as follows:

"…I'm not the same any more… I would say it (the illness) actually made me grow weaker. I'm now HIV+ and I was shocked and I don't get much of an appetite any more. The only thing I drink a lot of is water…" (Maggie)
"…ek is nie meer dieselfde nie… Ek sal maar so sê, dit (die siekte) het my eintlik laat swakker raak. Ek is nou HIV+ en ek was geskok en ek kry nie meer baie eetlus nie. Al wat ek baie drink is water…" (Maggie)

As previously discussed in this chapter, weight loss caused the participants in the present study extreme physical and emotional distress (see section 5.3.1 and section 5.4.1.2)

Ann and Rosy, like many other participants, verbalised that their desire for intimacy and sex decreased:

"Don't really do anything sexual with each other any longer…And he (her husband) mustn't touch me." (Ann)
"Worry nie eers met mekaar eintlik meer nie… En hy (haar man) moenie aan my vat nie." (Ann)

"I feel um now when he (her husband) has sex with me, I'm not like I used to feel with him…It has changed completely… no love and no uh strength in me for him…" (Rosy)
"Ek voel um nou as hy (haar man) met my seks het, ek is nie soos ek gewoonlik gevoel het met hom nie… Dit het heeltemal verander… niks liefde en niks uh krag in my vir hom nie…" (Rosy)

Hester, like most of the participants, conveyed a decline in energy levels, which had a negative effect on performing her daily duties:

"I have my children I was very fond of children, I worked, I felt full of life. I always felt like going to work, but now I don't have strength any more to want to get up in the mornings to to want to get up to go and work. I feel exhausted Elsa I don't feel like fetching waters." (Hester)

"Ek het my kinders ek was baie lief vir kinders, ek het gewerk, ek het lewenslustig gevoel. Ek het altyd gevoel om te gaan werk, maar nou ek het nie meer krag om soggens te wil opstaan om om te wil opstaan om te gaan werk nie. Ek voel gedaan Elsa ek voel nie om waters aan te dra nie." (Hester)

Many participants, like Sylvie, conveyed a decline in energy and loss of interest in daily activities:

"…I'm now just tired I'll just sit for a little while and then my thoughts have turned against me again. Then I just have to do something, because many times I don't know what there really is to do." (Sylvie)

…ek is nou net moeg ek sal maar so bietjie sit en dan het my gedagtes nou weer teen my gedraai. Dan moet ek net iets doen, want baie kere ek weet tog nie wat is daar eintlik om te doen nie…" (Sylvie)

Findings from the study conducted by Hudson et al. (2003) suggested that women living with HIV are distressed, at risk for depression, and have just a moderate level of overall functioning while they are caring for young children. Miles et al. (cited in Hudson et al., 2003) also reported activity limitations and at-risk levels of depressive symptoms in their study of African American mothers living with HIV infection.

Problems with concentration were also reported by some of the participants:

"I sit I just sit, it's as if something is putting my thoughts to sleep, Elsa. Then sit, I have completely forgotten something is burning inside that I must go and look at. When I get there the thing has already burnt and then I have to start from the beginning. It feels to me as if the HIV virus has taken something away from me." (Hester)

"Ek sit ek sit net, dis soos iets wat my gedagtes aan die slaap maak Elsa. Dan sit, ek het skoon vergeet daarbinne brand iets wat ek moet na gaan kyk. As ek daar kom dan het die ding nou gebrand en dan moet ek van vooraf begin. Dit voel vir my die HIV virus het iets weg van my af gevat." (Hester)

"… after I'd heard that I'm HIV+ I became very quiet like I never used to be. I also think a lot and I I don't concentrate so well on things like before or things that people say to me or that perhaps happen in front of me or so, because it takes away my attention a bit. And I'm no longer the same … if I still get someone to talk with, like P (partner), I will still talk, but I um in other words I… he talks, but I don't even listen to what he says. My attention is only on what the sister said to me HIV-positive, HIV-positive. I mean almost like a machine in my head. Then he has to nudge me, then I get a fright then I'm awake. It's almost as if I'm asleep when somebody talks to me or so…" (Maggie)

"…nadat ek gehoor het ek is HIV+ het ek baie stil geraak soos ek nog nooit was nie. Ek dink ook baie en ek, ek konsentreer nie lekker op dinge soos voorheen of dinge wat mense vir my sê of wat miskien voor my

gebeur of so nie, want dit vat 'n bietjie my aandag weg. En ek is nie meer dieselfde nie... as ek nog iemand kry om saam mee te gesels, soos P (mansvriend), sal ek nog gesels, maar ek um in ander woorde ek... P (mansvriend) gesels, maar ek luister nie eers wat hy sê nie. Al waarop my aandag is, is op wat die suster vir my gesê het HIV positief, HIV positief. Ek meen amper soos 'n masjien in my kop. Dan moet hy aan my stamp, dan skrik ek dan is ek wakker. Dis amper of ek aan die slaap is as iemand met my praat of so..." (Maggie)

The above statement shows that Maggie struggled to concentrate and to pay attention when other people were communicating with her. Research studies have found that depressive symptoms are experienced and expressed in bodily terms through a wide collection of somatic symptoms. Sowell et al. (1999) stated that many of the somatic symptoms associated with depression, for example loss of appetite, reduced concentration, sleep disturbances and tiredness, are also generally associated with HIV-disease progression. In the study conducted by Murphy et al. (2002), depression was associated with the mothers being less capable to perform tasks that they normally do and consequently children had more responsibilities for errands and household tasks. Servellen et al. (cited in Withell, 2000) found that fatigue in HIV-positive women is strongly correlated with socio-economic circumstances such as unemployment and dependent children, as well as depression.

Sowell et al. (1999) argued that somatic depressive symptoms may be confused with signs of HIV-disease progression, and health practitioners may fail to initiate effective or appropriate treatment of depressive symptoms that could enhance and maintain well-being.

5.8.3 Death and suicide ideation

Hester, Bertha and Rosy, like many participants in the present study, experienced such intense despair that they saw death as salvation. They called to God to take them away from this life, "die Here moet my weg vat", because through dying they could escape the pain and agony the illness caused them:

"When I'm so seriously ill then I think, but why doesn't the Lord then take me away. Why must I suffer so. It feels to me like this Elsa, because I go to doctors I go to hospital, but it always remains everything everything just remains the same." (Hester)

"As ek so ernstig siek is dan dink ek, maar hoekom vat die Here my dan nie weg nie. Hoekom moet ek dan so ly. Dit voel vir my so Elsa, want ek gaan na dokters ek gaan hospitaal toe, maar dit bly altyd alles alles bly net dieselfde." (Hester)

"No sister, I don't worry any more, I must rather just stay like this until I die altogether… If some day I perhaps get really ill and so and I feel thin and I become weak and so, then the Lord can just come and take me away. This is how I'm thinking of myself, then I just cry there at the back…" (Bertha)

"Nee suster ek worry nie meer nie, ek moet eider maar net so bly tot ek heeltemal gaan dood gaan… As ek die dag miskien nou rêrig siek raak en so en ek voel nou maer en ek raak nou af en so, dan kan die Here maar vir my weg vat. So dink ek aan myself, dan huil ek sommer daar agter…" (Bertha)

"Now if I don't get company then it comes to my mind again, oh dear I have such a difficult time and I become despondent. Then I think the Lord can just come and fetch me and sometimes when I also feel so sick then I think the Lord can just take me away I don't want to suffer so any more… Sometimes I get confused, then I think oh heavens and then I talk to myself and then I think oh heavens just take me away." (Rosy)

"Nou as ek nie geselskap kry nie dan kom dit weer by my, ag jinne ek kry so swaar en ek raak moedeloos. Dan dink ek die Here kan maar my kom haal en somtyds as ek so siek ook voel dan dink ek die Here kan my maar weg vat ek wil nie nog ly so nie... Somtyds raak ek verstryd, dan dink ek ai jinne en dan praat ek met myself en dan dink ek ai jinne vat my tog net weg." (Rosy)

Not only did certain participants pray that God must relieve them through death, some also thought of suicide as a means to escape their agony. Most participants reported thinking of suicide shortly after they had received their HIV-positive diagnosis (see section 5.1.3 of this chapter). Only a few participants reported ongoing suicide ideation:

"To kill myself sister, take pills, take poison… I've even thought of throwing myself under the train (subject cries)… My problem is just my family, they don't love me…" (Mariana)

"*Om my dood te maak suster, pille drink, gif drink… Ek het al gedink om my onder die trein al te gegooi het (subjek huil)… My probleem is net my familie, hulle is nie lief vir my nie…" (Mariana)*

"Oh Elsa, I would then, then I would probably want to commit suicide (if her HIV-status became known). And in the first place it felt to me so as if I should do it." (Hester)

"Oe Elsa ek sal dan, dan sal ek seker selfmoord wil neem (indien haar HIV-status bekend word). En in die eerste plek het dit vir my so gevoel ek moet dit doen." (Hester)

"No Elsa it just feels... they (friends) make remarks, ooh what's this now again and what's that now again. Then it feels to me ooh as if I could take my own life, when am I ever going to get well?" (Hester)
"Nee Elsa dit voel net... hulle (vriende) maak opmerkings, oe wat is nou weer dit en wat is nou weer daai. Dan voel dit vir my oe ek kan my eie lewe neem, wanneer gaan ek eendag gesond word?" (Hester)

Catz et al. (2002) stated that a woman's HIV-positive diagnosis is often accompanied by depression, suicidal ideation, suicide attempts, anxiety and other somatic and psychological symptoms of distress. In the study conducted by Leenerts and Magilvy (2000), some women participants described very destructive responses to their diagnosis, such as substance abuse and suicide plans. According to Heath and Rodway (1999), recent research indicated that the risk of suicide among people with HIV/AIDS is 36 times that of the general population. As in the present study, the HIV-positive women who participated in the study conducted by Withell (2000) also reported feelings of hopelessness and some contemplated suicide.

Sherr (1995) stated that suicidal thoughts and acts in association with HIV/AIDS tend to be concentrated around the time of diagnosis and again at the end stage of the illness. According to her suicidal problems may differ systematically for those in the two peak periods. She stated further that the trauma of an early diagnosis and infection/illnesses may trigger suicidal ideation or acts for some. This may be associated with the way in which testing was carried out, support at the time of diagnosis, individual ability to cope, social support and emotional resources. In the end stage suicide can be triggered by diverse factors, such as patients questioning the quality of their lives. Very often the burden of life in the presence of HIV/AIDS is too difficult to bear. According to Sherr (1995) suicidal acts are a form of taking control for some people who feel that control in many areas of their lives is elusive in the presence of HIV/AIDS.

For some of the participants in the present study death meant relief from pain and agony caused by their illness, but it also meant escaping rejection inflicted on them by others, and thereby their state of loneliness and despair.

5.8.4 Summary

The citations of participants in the present study show that they experienced numerous depressive symptoms. Experiences of sadness, hopelessness, and despair were prominent from the time of diagnosis till the time of the interviews. For some of the participants death meant salvation from the physical and psychological pain and distress caused by the illness. Various somatic symptoms of depression, such as insomnia, hypersomnia, concentration problems, decline in energy levels and weight loss, were also evident in the participants' citations. Several research studies have proved that many women with HIV/AIDS suffer from depression and that this has a detrimental effect on the acceptance and management of their illness (Catz et al., 2002; Olley et al., 2003; Richardson et al., 2001; Skolnick, 2002).

A number of psychosocial studies focusing on women living with HIV/AIDS, especially minority and low-income women, have found that women consistently reported significantly higher levels of depressive symptoms than men (Catz et al., 2002; Sowell et al., 1999). According to Catz et al. (2002) and Murphy et al. (2002), the differences in distress levels between women and men are ascribed to discrepancies in contextual and sociocultural issues, such as poverty, childcare responsibilities, responsibilities of caring for others infected with HIV, and the stigma and social isolation that women living with HIV experience. In the study conducted by Bunting (cited in Bunting, 2001) stigma was a primary predictor of depression in the caregivers who were often HIV-infected themselves.

Richardson et al. (2001) found in their study that depressive symptoms among HIV-positive women were very high and significantly related to not having family members or friends who listened to their concerns, experiences of domestic abuse, lower income, lower education, and alcohol abuse. Catz et al. (2002) found in their study that three-quarters of

the women participants reported mild to severe depressive symptoms and that their anxiety levels were higher in comparison with those of community norms. These participants described a series of life stressors that were consistent with previous findings among people from a lower socio-economic status. Kalichman et al. (2002) found in their study that women who were not receiving ART (antiretroviral treatment), like the women in the present study, were also more depressed than those being treated. Their study confirmed the association between current depression and HIV treatment. Thus, the sociocultural context could have a detrimental effect on the degree of psychological distress low-income women with HIV/AIDS have to endure.

In the literature it is stated that coping strategies within a specific sociocultural context can have an important influence on HIV-infected women's experience of psychological distress. Kaplan et al. (1997) stated that disadvantaged women of colour are more likely to report feeling responsible for their illness and keeping feelings to themselves compared to white women. Silence, concealment and avoidance were associated with higher levels of psychological distress such as depression (Siegel et al., cited in Simoni & Ng, 2000). In the study conducted by Simoni and Ng (2000), the frequency of concealment and avoidant coping used by HIV-positive women, as well as the levels of depressive symptomatology, were generally high and were both associated with lower income, less education and unemployment as well as a lack of social support. These findings show a correlation with findings from the present study. The participants in the present study were from a lower socio-economic status and they frequently used emotion-focused coping such as secrecy, concealment, and avoidance by withdrawing and escaping (alcohol abuse).

In addition, research showed that the reproductive years is the time period at which women are at greatest risk for HIV infection, and it is also the time at which women are at greatest risk for depressive symptoms (Sowell et al., 1999). According to Sowell et al. (1999), related research found that women at highest risk for HIV/AIDS experienced significantly higher levels of depressive symptoms than those women at lower risk. The participants in the present study were minority low-income women in their reproductive years, living in disadvantaged/poor communities within which women are often

disempowered. These factors most likely contributed to their experience of depressive symptomatology. Research data reported in the literature as well as data from the present study show certain dissimilarities regarding the illness experiences between HIV-infected women and men; HIV/AIDS can therefore be seen as a gendered construction.

It is suggested that within the dominant discourse of HIV/AIDS as a deadly and incurable illness, an illness which is shameful and blameworthy, an illness which is associated with secrecy, separation, suffering, loss, and loneliness, the participants experienced anxiety, hopelessness, despair and grief at not being able to change their circumstances and destiny. It seems that for them there was not much hope for a prosperous future and long life. Given the context of the participants' lives and their specific socio-economic circumstances, their lack of emotional and social support from friends and family, abusive relationships, substance abuse, economic hardships, and absence of treatment options, as well as their experience of an incapacitating, incurable, stigmatised illness causing them severe psychological distress, it is argued that the majority of the participants in the present study were in some state of depression.

5.9 Conclusion: the meaning and experience of HIV/AIDS

The qualitative research goal was to gain an understanding of how low-income Coloured mothers describe their experiences of being HIV-infected, and to explore the psychosocial concerns and mental health needs of these mothers in everyday life.

5.9.1 Psychosocial distress and mental health needs

The present study was conducted within the framework of social constructionism, which advocates for a focus on people's experience and understanding of their own illness within their specific social and cultural contexts. It therefore expands the scope of the study of illness and health from a focus on illness behaviours to how people understand and experience those behaviours. In the literature it is emphasised that the distress

experienced by low-income HIV-positive women living in disadvantaged communities should be understood from their perspectives and within the context of their lives and specific circumstances. The participants in the present study were low-income minority women living in disadvantaged and poor communities.

The participants' construction of AIDS was that of a life-threatening illness with no known cure. For them it meant a death sentence that left them with very little hope for a future life. The participants constructed HIV/AIDS as an illness that causes extreme physical and psychosocial distress. The participants were distressed about their own illness condition and the effect it had on their children, their lives in general, and their futures. They were also particularly concerned about their children's well-being, as well as daily survival and stressors. From the literature it is clear that these concerns are shared by many HIV-infected women, especially from disadvantaged communities.

The participants were exceptionally concerned from the time of diagnosis about their children's welfare and their childcare responsibilities, being the primary caretakers of their children. Their experiences of guilt about the possibility of abandoning their children through death seemed to be shaped by a belief that they would then fail as primary caregivers and mothers. Discourses of mothering, what it means to be a "good" woman/mother, were dominant discourses traced throughout the text.

An HIV-positive diagnosis was constructed by the participants in the present study as very traumatic, a powerful psychological shock that caused them immediate emotional distress and prompted the majority of them to contemplate suicide. From the time of diagnosis till the time of the interviews the participants suffered intense sadness, hopelessness, loneliness, anxiety, and despair regarding their illness condition, the consequences thereof and their lives in general. Heath and Rodway (1999) pointed out that frequent themes in the literature concerning the emotional impact of HIV infection are feelings of shame, low self-esteem, uncertainty about the course of the illness, fear of rejection, fear of death, feelings of loss of power and control, depression and suicidal ideation. In the present study these themes were also prominent in the participants' constructions of their

experience of being HIV-infected. In their accounts of their process of finding out about their diagnosis, there were at least three discourses that could be traced: a discourse of HIV/AIDS as an incurable and deadly illness; a discourse of HIV/AIDS as a shameful illness that someone should be blamed for; and a discourse of mothering, what it means to be a "good" mother. These discourses seemed also to be evident in their descriptions of living with HIV/AIDS as an illness.

In the present study, fear of disclosure from the time of diagnosis was especially prominent in the narratives of the participants. The participants' construction of HIV/AIDS as stigmatised, shameful, morally wrong, and blameworthy was widely shared in their communities and people treated HIV-infected persons accordingly. In their communities a person with HIV/AIDS is constructed as disgraceful, "bad", an "outcast", and therefore a person that will be avoided, rejected and victimised. Given these constructions of HIV/AIDS, the participants feared disclosure, but also feared that others would guess their HIV-status. Consequently, most of the women kept their diagnosis a secret or disclosed only to specific trustworthy persons. Some of the participants' diagnoses were known or guessed by other people, and as feared by all of the participants, these women were avoided, scolded, abused and rejected. Understandably, the majority of the participants withdrew and isolated themselves from others. In the participants' accounts of their illness experience a discourse of HIV/AIDS as an illness that a person should be ashamed of and be blamed for, as well as a discourse of secrecy and silence, could be traced.

The stigmatisation of the illness had an extreme and detrimental effect on the participants' psychosocial functioning as well as the management of their illness condition and their performance of daily tasks. Moneyham et al. (cited in Leenerts & Magilvy, 2000) confirmed that experiences of stigmatisation affect health outcomes, including mental health and quality of life. Sowell et al. (1999) stated that concerns about stigma, revealing one's HIV-status to others, and victimisation, may disrupt earlier caring and helpful relationships and prevent women with HIV/AIDS from utilising much needed sources of support. In the literature it is stated that women have introjected social views and feel more ashamed of their status, regardless of how they became infected (Broun, 1999). The

narrations of the participants in the present study show that stigmatisation and experiences of rejection may lead to secrecy and isolation, and, consequently, to not receiving support and care in various areas of their lives. These findings suggest a gendered discourse of silence: a woman with HIV/AIDS should keep her illness a secret.

It is evident in the participants' accounts of their illness experiences that HIV/AIDS was constructed as an illness associated with extreme physical suffering, pain, and loss. HIV/AIDS was further constructed by the participants as a debilitating illness that causes the body to deteriorate visibly. Weight loss as the most visible symptom of being HIV-infected was very prominent in the narrations of the participants. The participants' construction of HIV/AIDS as an illness associated with weight loss caused the women to fear that others would identify them as HIV-infected and then reject or victimise them. The physical illness symptoms experienced by the participants had a harmful effect on their womanhood (physical appearance) and motherhood (caring for children and home). Because their experiences of physical suffering, fatigue, and pain and the loss of physical strength affected their functioning as homemakers and primary caregivers negatively, they felt that they were failing as women and mothers.

In the participants' citations it was clear that the construction of an ideal woman/mother is a construction of a woman that is the primary caregiver, a woman that is self-sacrificing, one who puts others first even if in pain or distress herself. According to Kneisl (cited in Gillman & Newman, 1996), women with HIV/AIDS must cope with sources of stress and anxiety different from those of infected men: "...women generally have fewer economic resources, more role responsibilities (caring for family members, children and generating income), and fewer social and community supports than do men" (p.132). Research studies indicated that HIV-positive women are particularly distressed by responsibilities and demands placed on them by family members, and many women reported greater physical and psychological symptom distress and substance use (Murphy et al., 2002).

In the present study, stigmatisation, shame, fear and experience of rejection, abandonment and abuse as well as concerns regarding physical appearance and illness

symptoms manifested in a subjective sense of immense loss in most participants. It meant the loss of self and the loss of a way of life, of woman- and motherhood, of a family life, of productivity, of normal social interactions, human contact and care. These losses experienced by the participants caused them to become extremely lonely and furthermore deprived them of sufficient and much needed emotional, social and practical support and care. In the literature it is emphasised that women with HIV who are in their reproductive years, mothers of children, and impoverished, with the most insufficient resources and least access to care, experience more severe symptom distress on a physical and psychological level than those who receive prompt treatment, support and care (Sowell et al., cited in Sarna et al., 1999).

Given the construction of HIV/AIDS as an illness that people should be ashamed of and be blamed and rejected for, and consequently an illness that has to be suffered alone, it is understandable that coping strategies such as concealment, withdrawing, disconnecting and escaping (use of alcohol) became the norm for the participants in the present study. It can be argued that the lack of emotional and social support, in terms of coping resources, played a significant role in the prevalent use of emotion-focused coping that was found among the participants in this study. Various research findings show that coping strategies used by women with HIV/AIDS are very specific to the context of the illness and unique to the socio-economic circumstances of women's lives (Raganya, 2003; Sowell et al., 1999). In South Africa, alcohol abuse is particularly problematic in communities where women are exposed to abuse, victimisation, and unemployment and have many family caregiving responsibilities (Beake & Goosen, 1996). Women turn to substances to ease and cope with stressful living conditions. Research showed that women with HIV/AIDS who use alcohol have less energy, poorer social functioning and lower independent functioning levels with regard to daily activities, and lower overall quality of life (Vosvick et al., 2003). Although fear of disclosure, secrecy and social withdrawal were prominent in the narrations of these women, many of them revealed a strong need for acceptance and psychosocial support.

Research data on HIV/AIDS and women as well as the findings of the present study show that women's experiences of the illness are unique and different from those of men, primarily as a result of their place and social status within their sociocultural contexts. Several issues affecting women's ability to respond positively to their illness and stay healthy are based on women's historical role in society, such as expectations and responsibilities that women face within the context of the home, family and community. According to Heath and Rodway (1999), research studies that focused exclusively on women's psychosocial issues and AIDS found that gender, power and control were central themes. Ackermann and De Klerk (2002) and Sowell et al. (1999) argued that the restrictions and limits of power, control and economic resources and the continuing dependency of women in our society are factors that not only contribute to the HIV/AIDS risk of certain groups of women, but also impact how women experience and cope with the illness. Gillespie (cited in Cohan & Atwood, 1994) reported that so many of the attitudes about women's worth and place and men's rights that permeate societies make successful prevention campaigns and adequate healthcare extremely difficult to achieve. From the narrations of the participants in the present study it seems that they were disempowered within their intimate relationships, within their families as primary caregivers and homemakers, and within their socio-economic circumstances.

The participants' construction of HIV/AIDS as an illness that had a detrimental and disempowering effect on them as women and people is shared by many other low-income women. Recurring distresses concerning HIV-infected women's social circumstances, such as worries about daily survival, inadequate emotional and social support and care, abuse and victimisation, substance abuse, poor self-esteem, self-neglect and -sacrifice, and silence, indicate why loss of self and psychological conditions such as depression may well occur in low-income HIV-positive women. For the participants in the present study, their physical condition, psychosocial losses, lack of support and care, stressful living conditions, and alcohol abuse contributed to their experiences of loneliness, anxiety and depressive symptomatology. Psychological distress and conditions such as depression, anxiety, and loneliness have been frequently identified in HIV-infected, low-income single mothers (Rokach & Brock, 1998).

The participants experienced anxiety about the duration of their lives, their own and their children's futures and what these entail, how they would die, the illnesses and suffering accompanying the dying process, and death itself. Given the construction of HIV/AIDS within their community as an incapacitating and incurable illness that ultimately leads to death, women with HIV/AIDS will understandably experience intense fears regarding suffering and the dying process. The anxieties and fears experienced by the participants in the present study regarding their lives and the possibility of an early death, and their deep concern about and dilemma of not being able to change their fate, led to feelings of intense loneliness, sadness, hopelessness, despair and grief.

It is suggested that an incompatibility exists between the dominant discourses found in the participants' accounts of their illness experiences: an incompatibility between the meaning of HIV/AIDS as an illness (a deadly and incurable illness, a shameful and blameworthy illness, an illness of secrecy, separation, pain and suffering, loss, and loneliness), and the discourse of mothering, what it means to be a "good" woman/mother (the primary caregiver of children, someone who is connected, physically strong, healthy and productive, and someone who is able to cope with her caregiving responsibilities even when in distress herself). It seems, then, that these distressing experiences of being HIV-infected and a primary caregiver and mother of children caused the participants in the present study further psychological distress and suffering.

5.9.2 Depression

In the literature it is clear that depression has been frequently identified in HIV-infected low-income women. The majority of women with HIV/AIDS are disadvantaged, poor, single mothers who are unemployed, and have little education, all factors that have been correlated with psychopathology such as depression. Hackl et al. (1997) found that all the HIV-infected caregiving women in their study revealed evidence of clinical depression. These writers stated further that traditional caregiving responsibilities of HIV-infected women are often complicated by lack of social support and feelings of grief and loss

accompanying their own terminal illness. According to Richardson et al. (2001), the high rates of depressive symptoms among HIV-infected low-income women most likely reflect the fact that many have experienced abusive relationships, substance use, and economic hardship as well as having HIV/AIDS. In the present study the women participants experienced their illness within a social context of stressful living circumstances, such as insufficient emotional and social support from friends and family, abusive relationships, alcohol abuse, multidimensional responsibilities, economic hardships, inadequate housing and social support services, and a lack of healthcare and antiretroviral treatment; all factors that have been correlated with depression.

Consequently, HIV/AIDS was a major crisis that the participants had to cope with, but not the only crisis in their lives. According to Moneyham et al. (cited in Simoni & Ng, 2000), the more one associates living conditions and life stressors with having HIV/AIDS, the more likely one is to appraise the illness as threatening, which in turn increases psychological distress such as depression. Simoni and Ng (2000) pointed out that these results suggest that disadvantaged women with HIV/AIDS, mostly women of colour, may be at greater risk for psychopathology such as depression, compared to their white counterparts with less stressful living conditions and better healthcare. Therefore, the socio-economic contexts, within which low-income women are generally disempowered, should also be considered as contributing to discourses on HIV/AIDS, psychological distress and depression.

Furthermore, it has been emphasised in the literature that there is a strong link between illness progression and depressive symptomatology. Results obtained from a study by Richardson et al. (2001) correlated with findings from previous studies indicating depressive symptoms being associated with progressive illness and illness symptoms. The participants in the present study constructed HIV/AIDS as an illness that causes severe physical discomfort and pain. The physical symptoms had a definite harmful effect on their daily functioning and psychological well-being. Visible illness symptoms, such as weight loss, caused the participants to fear being identified as HIV-infected and, consequently, being scorned and rejected. The participants reacted by withdrawing and

isolating themselves from others, which inevitably led to further psychosocial losses and loneliness. The study conducted by Van Servellen et al. (2002) found that the physical-health status of HIV-infected women was significantly related to emotional distress and their general psychosocial well-being. Conversely, women's psychological response to HIV infection, including the trauma of a positive diagnosis, may have implications for illness progression and survival (Earl et al., cited in Kaplan et al., 1997).

Kaplan et al. (1997) discussed an emerging body of literature in psychoneuro-immunology which suggests that psychosocial phenomena such as depressed mood, hopelessness and fatalism, anxiety and loneliness may accelerate the pace at which HIV progresses. Macks (1987) emphasised that the drastic alterations in lifestyle imposed by chronic fatigue, debilitation, the loss of mobility, and the loss of bodily functions as the illness progresses, can result in further isolation, loneliness, the increased use of drugs and alcohol, and depression. The majority of the participants in the present study had been diagnosed with HIV/AIDS for more than a year. Only one participant had been diagnosed for less than six months prior to the research interview. It is important to note that the five participants (Sylvie, Elna, Joeyce, Hester and Rosy) who had been diagnosed for more than one year, generally reported more serious physical symptoms than those women diagnosed for 12 months or less. These women were also extremely distressed and frequently narrated emotional states such as loneliness, sadness, pain, hopelessness, fear and despair – all emotional states that can be associated with depression.

Research studies also found that people with HIV/AIDS have complex grief processes; they become significantly more depressed and anxieties related to death are significantly greater than in the case of people diagnosed with cancer (Sherr, 1995). In the literature it is emphasised that HIV/AIDS is a much more stigmatised and condemned illness than cancer, and this may affect the grieving process, the degree of depressive symptomatology and overall psychological distress of HIV-infected women. Mullan, Pearlin and Skaff (2000) defined grief as "the complicated set of emotional and cognitive responses that accompany loss" (p.149). Although grief includes a variety of emotions, the principal emotion associated with grief is depression. Sherr (1995) stated that grief is not a single concept

but meanders in many forms through the course of an illness such as AIDS, therefore the effects of grief are cumulative and add disproportionately to the emotional burden. According to Mullan et al. (2000), it may be a low-grade dysphoria in people who continue to function in their normal social roles but who live their lives in an emotional valley, or it may be more severe, immobilising the person psychologically. According to Faithfull (1997), the grief observed in HIV-infected persons compares well with a typically pathological or abnormal grief reaction, which can enhance a depressive mood, anxiety, and loneliness. Therefore, given the discourses of HIV/AIDS as an illness of shame, secrecy, separation, physical suffering, and extreme psychosocial losses and loneliness, it is comprehensible that the participants experienced severe psychological distress, intense grief, and depressive symptomatology.

In the literature it is emphasised that psychological adjustment is a crucial aspect of HIV-infected women's overall well-being and quality of life. Antoni (2000) stated that the debilitating nature of HIV/AIDS, its unpredictable course, and the tendency of infected women to become withdrawn or to lose emotional and social support from significant others and their communities, put HIV-infected women at risk for prolonged mood disturbance and depression. In the present study the participants' construction of HIV/AIDS as a stigmatised, deadly and incurable illness to be kept a secret caused them extreme emotional and social isolation and deprived them of much needed support and care, which negatively affected their psychosocial adjustment and well-being after diagnosis. The participants were silenced and therefore unable to express and deal with their emotions regarding their illness and other life stressors. It seems that it was almost impossible for these women to deal or cope with their psychological distress, because their feelings were not heard or validated by important others or health professionals. Their progressive and intense experience of loneliness, sadness, hopelessness, anxiety and despair, prevented them from dealing with their many losses. It seems as if they were emotionally "trapped" in their illness and "stuck" in their states of depression and grief, and therefore not able to adjust to, or accept their illness condition and the probability of an early death.

Chapter 6

Summary of findings, recommendations and critical review

This chapter begins with a recapitulation of the main aim of the study in order to recapture the focus of the study. Thereafter the most important findings will be summarised. Recommendations for the provision of psychosocial support and mental healthcare for disadvantaged women with HIV/AIDS, as well as for future research on HIV/AIDS and women, will be presented. A critical review of this research study will conclude this chapter.

The goal of this research was to conduct an in-depth study of how low-income Coloured mothers in the Winelands Region of the Western Cape describe their experiences of being HIV-positive. The study was a systematic analysis and documentation of how the illness (HIV/AIDS) was constructed in narratives of these women. The operationalisation of the research goal was to explore the psychosocial concerns and mental health needs of HIV-infected, low-income Coloured mothers in everyday life; to construct a testable Grounded Theory regarding the illness experience of low-income Coloured mothers; and to recommend guidelines for health workers.

6.1 Findings

The participants' construction of an HIV-diagnosis was that of being extremely traumatised, a life-altering event, a devastating and irreversible condition, and a death sentence. The illness experience of the participants can be divided into two stages: finding out about the illness (the time of diagnosis) and living with the illness (after the diagnosis). Feelings of intense sadness, hopelessness, loneliness, anxiety, despair, and grief were experienced at the time of diagnosis and thereafter. The participants' construction of HIV/AIDS was that of an extremely stigmatised, incurable and deadly illness, which

differentiates it from almost all other chronic illnesses. The stigma attached to the illness caused the participants to experience blame, rejection and abuse/victimisation by family, friends and the community. The participants also felt ashamed of their positive status and therefore withdrew from important others and the community, and, consequently, became extremely lonely and isolated. Given a discourse within which HIV/AIDS was constructed as a fatal illness, and an illness to be ashamed of or to be blamed for, the participants responded mainly by keeping their status a secret. Thus, the construction of the illness as a silent one meant it was also a lonely one.

The participants constructed HIV/AIDS as an illness that caused them extreme physical and psychosocial distress and losses. The experience of psychological distress, as well as physical illness symptoms, had a harmful effect on the management of their illness condition, the performance of their daily duties as primary caregivers and homemakers, and their general psychosocial well-being. For the participants a “good” or “ideal” woman seemed to mean someone who takes care of her children and family regardless of her own needs and physical limitations. Because the participants felt that they were not succeeding in living up to constructions of ideal womanhood and motherhood, collectively constructed in their communities, they felt that they had lost their worth as women and as people. This contributed to their withdrawing and isolating themselves from others even more.

The participants’ constructions of HIV/AIDS as an illness that is associated with stigma, shame, blame, withdrawal and silence, as well as with physical decline and suffering, caused them to experience immense psychosocial losses and loneliness. Given these constructions of HIV/AIDS, the participants primarily used coping strategies such as secrecy, concealment, social withdrawal and escaping (use of alcohol), which most probably kept them from dealing with their stressors in more healing ways. Furthermore, these illness experiences deprived the participants of potential emotional, social and practical support and care, which they were in great need of. It seems that the participants were disempowered as women and persons for being HIV-infected, for being expected to be the primary caretakers of children, for being in abusive relationships, and for living in poor conditions where they had to struggle for daily survival.

All the above constructions of what it means to live with HIV/AIDS as an illness contributed to intense psychological distress and pain, such as anxiety and concerns regarding issues of life and death. The anxieties and fears experienced by the participants regarding their future lives and early death, suffering and pain accompanying the dying process, and their deep concern about and dilemma of not being able to change their destiny, intensified their grief and depressive feelings. Therefore, the grieving processes of these women can be described as complex as they were not yet able to adjust to, or accept their illness condition and the consequences thereof.

6.1.1 Key themes identified

Important and central themes identified in this study were:

- Stigmatisation
- Fear of disclosure
- Blame, rejection and abuse/victimisation
- Shame, withdrawal and loneliness
- Living a secret
- Physical losses, pain and suffering
- Loss of womanhood, motherhood and personhood
- Concerns regarding children
- Primary caregivers and related stressors
- Poverty
- Alcohol abuse
- Gendered power relations
- Disempowerment
- Hope for cure and future
- Faith
- Fear of suffering, pain and dying
- Death and suicide ideation

- Depression (sadness, hopelessness, despair)
- Grief
- Need for bio-psychosocial support and care
- Need for love and acceptance.

All these themes highlight important and crucial issues, distresses and needs experienced by the women participants in the present study that call for serious attention by healthcare providers.

6.1.2 Building theory: discourses

In the participants' accounts of their illness experience, two dominant discourses were identified. The first was a discourse of HIV/AIDS, within which the illness was constructed as a stigmatised, incurable, and deadly illness; as a shameful illness that someone should be blamed for; and as an illness associated with secrecy, silence, separation, pain and suffering, loss, and loneliness. The second dominant discourse identified was a discourse of mothering, what it means to be a "good" woman/mother; this was constructed as someone who should primarily take care of her children and family, and not be separated from them, or neglect or abandon them through illness or death. It is suggested that the two dominant discourses found in the participants' accounts of their illness experiences, namely the meaning of HIV/AIDS as an illness (a stigmatised, incurable, and deadly illness, a shameful and blameworthy illness, an illness of secrecy, silence, separation, pain and suffering, loss, and loneliness), and the imperatives of mothering, what it means to be a "good" woman/mother (the primary caregiver of children, someone who is connected, physically strong, healthy and productive, and someone who is able to cope with her caregiving responsibilities even when in distress herself), are irreconcilable.

It seems that these distressing and disempowering experiences of being HIV-infected while also being a primary caregiver and mother of children caused the participants in the present study severe psychological distress and suffering. Given these discourses and the

context of the participants' lives within their specific socio-economic circumstances, their lack of emotional and social support from friends and family, abusive relationships, substance abuse, economic hardships, and absence of treatment options, as well as their experience of an incapacitating, incurable, stigmatised illness causing them severe physical and psychological distress, it is argued, then, that the majority of the participants in the present study were in some state of depression.

6.2 Recommendations

The findings of the present research indicate that a range of physical and psychosocial issues, impacting on quality of life, determine the health and well-being of women with HIV/AIDS. These findings emphasise that a major focus of care for women with HIV/AIDS should be on the psychosocial aspects of the illness and not only on the physical treatment of illness symptoms. In biomedicine, the main focus has been on finding cures rather than preventing ill health or providing holistic and quality healthcare. The findings in the present study show that emotional, social and spiritual issues can enhance or hamper the physical management of the illness, just as physical well-being can influence psychosocial functioning. Therefore, an integrated view of biological, psychological and social issues/needs is recommended for research agendas as well as when planning and rendering medical and psychosocial support services and care, with the ultimate goal of enhancing the duration and quality of low-income HIV-infected women's lives.

Disease is taken to represent the medical model and illness the patient's subjective experience within a specific social context. The medical model promotes individual solutions to most health problems and, as a result, women are discouraged from finding more social or cooperative ways of empowering themselves to solve problems regarding their health. From a social-constructionist viewpoint, individual behaviour cannot be observed in isolation from sociocultural circumstances and the power relations within these circumstances. Gwyn (2002) pointed out that illness tends to correlate with the psychological, moral and social explanatory models of any given culture, so that the same

objectively defined disease would not be experienced as the same illness by individuals in distinct societies. Thus, social constructionism discloses the real concerns of and problems of power for HIV-infected women, by focusing on the context of the individual. It is argued, then, that contextual changes within the healthcare system, as well as within women's living environment, can facilitate the empowerment of women. Although power has a significant social-structure component, it also has important interpersonal components that should be considered in the provision of healthcare for women. Social-structure factors like social status and access to opportunities, in addition to interpersonal issues like personal skills, competence, and knowledge, can play a central role in shaping power. Thus, the needs of HIV-infected women should be met on both micro and macro structural levels.

The emotional effects of being HIV-positive were compounded in the women participants in the present study, who were already prone to high levels of anxiety and depression as a consequence of being disempowered by their low socio-economic status, multiple and stressful caregiving responsibilities and daily struggles for survival. Thus, responding to the health needs of low-income women with HIV/AIDS necessitates viewing HIV/AIDS within the social context of the family and the community. Brown (cited in Lorber, 1997) emphasised that for patients and healthcare professionals, illness entails all the patterns of social life, interwoven social roles, power and conflict, social statuses, networks of relatives and friends, bureaucracies and organisations, social control, beliefs of moral worth, aspects of work and occupations, definitions of reality, and the production of knowledge.

Acknowledging and challenging the social context, in terms of gendered power relations and economic dependence of HIV-infected women, is of the utmost importance. In the lives of the participants in the present study, as in the lives of many low-income HIV-infected women, gendered power relations related to their experience of interpersonal abuse as well as victimisation and exploitation within their families and communities, which had a detrimental effect on their psychosocial functioning and well-being. Therefore, the inequality of gendered power relations needs to be confronted and challenged in research, prevention, and healthcare programmes for low-income women. Strebel (1993) argued

that we are confronted by a complex web of contradictory representations in which the specific historical contexts of the AIDS epidemic in South Africa, plus dominant AIDS discourses and discourses of gendered power relations, which are both mediated by economic forces, make effective AIDS prevention and treatment especially difficult for women in this country.

It is therefore recommended that, when planning, developing and rendering appropriate and quality medical and mental healthcare and psychosocial support/services for women, providers need to consider the special bio-psychosocial needs of women within their specific sociocultural and economic contexts. To identify these needs necessitates the discovering and revealing of the dominant discourses in the narratives of HIV-infected women. Thus, to be able to hear, understand and give voice to AIDS narratives in South Africa, it would be vital to identify the concrete and theoretical nature of AIDS in different cultures and communities. Treichler (1999) stated that theories and concepts must be pursued that describe and elucidate how illness is constructed differently in different historical and cultural settings. The focus of AIDS research should therefore be on understanding how individuals and groups construct and experience HIV/AIDS in different contexts, and not on attempting to determine what is true about the illness for most people in general (Treichler, 1999). Research conducted within a social-constructionist framework can contribute to such identification and, ultimately, to the planning and provision of social- and cultural-context appropriate and effective medical and psychosocial support services and programmes for low-income women with HIV/AIDS.

> We cannot therefore look ‘through’ language to determine what AIDS ‘really’ is. Rather, we must explore the site where such determinations really occur and intervene at the point where meaning is created in language... New meanings of HIV/AIDS can offer new possibilities for action and can foster change in different cultural communities; the observer must go beyond simply the desire to understand or even to describe the other culture; the researcher must let it speak and then give voice to the story it tells. (Treichler, 1999, p.11)

Following theorists such as Treichler, the major discourses that were operative in the illness experience of the participants in the present study were identified. It seems then that before one can even begin to consider more specific interventions such as assessing particular needs and responding to them, it is important to consider also intervening on the level of discourse. In other words, the discourses that so prominently shape the illness experience (and, consequently, the lives of participants) should be highlighted and the assumptions questioned, contested, and even replaced. In practice this might mean that psychologists would have to address on community level constructions of HIV/AIDS that lead to psychological distress such as hopelessness, despair, loneliness, and even depression. However, attention would also have to be paid to a mothering discourse within which a woman's worth is so closely connected to her ability to address the needs of her children, her partner, and her home. It is perhaps the prominence of this mothering discourse that results in an illness experience that is highly gendered.

6.2.1 Provision of psychosocial support and mental healthcare

Healthcare providers can play a fundamental role in optimising physical and mental health outcomes of disadvantaged and low-income women and mothers with HIV/AIDS. Several strategies can be implemented that may reduce morbidity as well as adverse psychosocial distress associated with HIV/AIDS in women, which ultimately may enhance the duration and quality of women's lives. The women in the present study, like most other HIV-infected women, needed assistance in adapting psychologically to the many physical and psychosocial changes that occur throughout the course of the illness.

6.2.1.1 Assessment of psychosocial distress and needs

In the present study it was clear that the women participants experienced severe psychological distress from the time of diagnosis. Many of these distresses intensified as the illness progressed. The needs and distresses of HIV-infected women should therefore be assessed from the time of diagnosis and throughout the course of the illness.

Healthcare providers should give HIV-infected women psychosocial support and care focusing on these specific needs and distresses. The following suggestions/guidelines are presented:

1. Healthcare providers should evaluate the emotional response of women at the time of diagnosis and be able to assess the risk for suicide.
2. Assessment of potential support structures (family, community, healthcare facilities and services) is also vital at this early stage, because of the tendency of women to keep their diagnosis a secret.
3. An HIV-diagnosis may lead to loneliness, anxiety, depression, and suicide ideation/attempts in women, therefore follow-up assessments, evaluations, counselling and care are of the utmost importance.
4. Subsequent stressors should be identified in all areas, namely 1) medical/clinical stressors (e.g. HIV/AIDS-related physical symptoms; opportunistic infections that signal a transition to AIDS; decline in daily and physical functioning); psychological stressors (e.g. loneliness, anxiety and depressive conditions and related psychological distress, other psychopathology; and substance abuse); family stressors (e.g. stigmatisation, rejection and abuse/victimisation by partners and family members; problems with childcare; relationship problems; care of infected family members; substance abuse by family members); socio-economic stressors (e.g. stigmatisation and victimisation; available support and care services; financial and housing problems; work-related problems, transport problems).
5. Family assessment of the influence and consequences of the illness on the woman's partner, children and other family members (or important others). This assessment should include how the illness affects family relationships and the general functioning of the family, and how different family members cope with the situation on an emotional and practical level. This assessment is very important when the woman is symptomatic, especially when the family experiences financial difficulties and practical problems, such as caring for the patient, and getting the patient to medical appointments. Providing information about the course and the physical treatment and care of illness symptoms, as well as their psychosocial impact, would

empower women and family members to manage traumatic times and stressful situations on the basis of accurate facts rather than fears.

6.2.1.2 Responding to the psychosocial needs of women with HIV/AIDS

Findings from the present study and from the research literature clearly show that women coping with HIV/AIDS have several physical, mental health and psychosocial needs regarding themselves as well as regarding the care of family members, especially their children. Therefore, gender-specific support services should be rendered to enable women to combat and manage their illness on a physical and psychosocial level, as well as to cope with their daily stressors and caregiving responsibilities. The following suggestions/guidelines are presented:

1. At the time of diagnosis women should be supported in a sensitive and caring manner. As the time of diagnosis is an extremely traumatising experience for women, healthcare providers should be trained in debriefing and listening skills.
2. Appropriate and adequate information on HIV/AIDS should be provided and discussed at the time of diagnosis and thereafter.
3. Issues regarding stigmatisation, secrecy, disclosure and potential support from family and community members should be addressed and managed from the time of diagnosis. When disclosure is a problem, women and their family members should be referred for counselling. Issues regarding stigmatisation should also be addressed on a macro structural level. Initiatives focusing on the de-stigmatisation of HIV/AIDS should be planned and implemented by the Department of Health and other healthcare organisations, especially since ART is now more readily available for low-income people in this country, and HIV/AIDS is thus becoming a more chronic and manageable illness and not an inevitable death sentence.
4. Psychological symptoms/conditions such as loneliness, anxiety, grief, depression, and substance abuse should be evaluated and monitored by healthcare providers, and referrals for counselling or psychotherapy made when needed.

5. Spiritual needs should be addressed by referring women to appropriate persons and organisations, taking their faith and religion in consideration.
6. Healthcare workers and counsellors should give women the opportunity to voice their feelings and experiences regarding their illness and other life stressors. These feelings should be validated by health workers/counsellors, especially those of women who experience abuse/victimisation and are emotionally and socially isolated.
7. Healthy life styles should be promoted, by addressing issues such as substance abuse, smoking, nutrition and exercise.
8. Counselling and therapy can help women to regain more control over their lives, which can reduce stress associated with their illness, poverty and abusive and disempowered living conditions. This entails improving their coping skills and management of their illness condition, coping with their caregiving responsibilities, and coping with additional and daily stressors in their lives. Healthcare professionals can help patients distinguish between the controllable and uncontrollable aspects of their illness and living conditions, and guide and support them to focus on those aspects that they can change and improve.
9. Psychosocial support and care is vital when an HIV-infected women is responsible for the care of other infected or ill family members, when she is a single parent, the only breadwinner, when she abuses substances, when she experiences a lack of support and acceptance from family members and the community, when she is exposed to abuse or victimisation, and when she has additional financial and practical stressors (e.g. problems with transport and childcare, lives far from medical and psychosocial health services and facilities).
10. Support groups for women with HIV/AIDS can empower women by offering much-needed information on the illness condition and management thereof, encouraging healthy living, safe sexual practices, and healthy coping strategies, providing emotional support and acceptance by others in the same situation, and alleviating feelings of loneliness.

Healthcare providers' main goal should be to empower women with HIV/AIDS to care for themselves, by using available psychosocial support services and agencies and being guided and skilled in selfcare practices in all facets of their lives. It is primarily important for HIV-infected women to realise that they are not alone with their illness.

6.2.2 Recommendations for future research on women and HIV/AIDS

Further research grounded in social-constructionist theory should be done on women with HIV/AIDS, focusing on how women make sense of their world and illness experiences within their specific social and cultural contexts. Such research initiatives should enhance our understanding of women's unique illness experiences, distresses and needs, with the ultimate goal in mind of utilising and implementing this knowledge so that women's distresses and needs can be effectively addressed and thereby their quality of life improved.

1. Extensive research studies need to be conducted on how low-income HIV-infected women from different cultures experience their illness, thereby gaining knowledge and understanding of how these women live their lives with HIV/AIDS and what their specific and unique distresses, concerns and needs are. To identify these distresses and needs necessitates the discovering and revealing of the dominant discourses in the narratives of HIV-infected women from different cultural communities. To be able to hear, understand and give voice to these narratives, it is of the utmost importance to identify the concrete and theoretical nature of AIDS in these different cultures. From the literature it is clear that other minority groups in South Africa, such as HIV-infected low-income white women, are overlooked in research agendas and also need to be studied.
2. Research studies focusing on the planning, implementation, and evaluation of psychosocial support programmes/initiatives for low-income, disadvantaged and minority women with HIV/AIDS are essential, so that existing research data of women's psychosocial distresses and needs can be put into practice.

3. Given the dominant discourse of mothering and caregiving revealed in the present study, extensive research studies focusing on mothers and children with HIV/AIDS need to be conducted. The distress and needs of both mothers and children, as well as the interrelationships between these distresses and needs, should be explored.
4. Studies on families with HIV-infected members, the effect of the illness on their relationships, functioning, distress and needs, as well as planning for future needs should members fall ill or die, could render important and useful data.
5. Alcohol abuse among Coloured HIV-infected women seems to be a cultural-specific and severe problem that should be included in research agendas.
6. With antiretroviral treatment (ART) being more readily available to low-income women in South Africa, it would be important to determine how this affects their illness experiences.
7. Economic issues, such as financial stressors and poverty, should be studied and analysed more extensively by researchers from appropriate disciplines. In the present study it was clear that financial limitations and stresses had a detrimental effect on the participants' general well-being and their ability to cope with their illness and daily lives.

6.3 Critical review of the research

The present research study was conducted within a social-constructionist framework that requires us to look at the situational context of women's lives and helps us understand women's experience of illness within their specific sociocultural structures.

1. The present study provided an informed understanding of the illness experiences for the sample of eleven HIV-infected Coloured South African women within their specific sociocultural contexts.
2. The qualitative data emerged as rich and detailed descriptions of the lived experiences of the participants. The researcher envisages that even more can

evolve from the data than what was presented in the present study. This can probably be achieved by using more interpretive analytical methods such as narrative or discourse analysis.

3. The generalisability of the study is compromised by the fact that the focus was on a very small group of women, all of whom were Coloured South African women living in the Winelands Region of the Western Cape. In Chapter 4 on research methodology it was explained that convenience sampling was used to recruit the participants, since because of stigmatisation it was problematic to find people who were HIV-infected and willing to share their personal experiences. The results are thus bound within a specific context and to a specific group of women. As has been stated in the previous section, future research studies could be extended to other groups of women within the broader South African context. Consequently, no real or universal construction and understanding of HIV/AIDS was hypothesised, and no generalisations about other groups were made on the findings that emanated from the data.
4. The researcher was involved in all the phases of the research process, thus co-constructing the interviews, findings and conclusions of this study. This involvement made it possible for the researcher to analyse the data from the interview phase and throughout. It also aided the researcher to become deeply involved with the research data, helping her to understand, interpret and describe the real experiences of the women participants. It is recognised that the subjectivity of the researcher impacted on all stages of the research process (through data collection, transcription, and data analysis). However, the scope of the present study did not allow for a more detailed analysis of exactly how the subjectivity of the researcher herself impacted on the results of the study. Conversely, the impact of conducting the research on the researcher was not discussed in any systematic way.
5. Although there were many advantages in conducting all the research phases herself, the researcher still remained an outsider looking in, being from a different cultural group and socio-economic status. Thus, the analysis, findings and conclusions of an insider researcher and interpreter might well have been different. However, it can also be argued that it was exactly the researcher's outsider status

that made it possible for the participants in this relatively small community to talk so openly about an experience that is considered to be so shameful and difficult to share.

6. Triangulation could be used to enhance the objectivity and reliability of a research study such as the present one. For instance, two researchers coding and analysing the same data may bring forth interesting results, especially if they are from different cultural groups.
7. The researcher's quotes and questions were not cited in the document and can therefore be criticised as being decontextualised. Citing the researcher's quotes most probably could have broadened or deepened the meaning of certain descriptions and experiences of the participants. Nevertheless, it was decided to primarily document the participants' experiences by focusing on their words and descriptions.

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The researcher attempted to understand and describe the participants' experiences, but also endeavoured to let these women speak and then to give voice to the stories they tell.

"People blame, um give us reproaches, they usually scold me that I don't have TB, I have AIDS and sometimes it hurts me man, sometimes I just feel I must sit apart and just talk to somebody who can support me. Then I feel so powerless then I can do nothing nothing for myself." (Hester)

"Mense verwyt, um gee vir ons verwyte, hulle skel vir my gewoonlik ek het nie TB nie ek het VIGS en sommige tye dan maak dit my seer man, sommige tye dan voel ek net ek moet eenkant sit en net met iemand gesels wat vir my kan bystane. Dan voel ek so kragteloos dan kan ek vir myself niks niks doen nie." (Hester)

"...I wish others should also treat me as any other person is treated. I don't want them to look at me with that attention or to pity me. Um yes, I would like them to love me because love is the thing I miss most in my life and then that's what I want for my child as well..." (Elna)

"...verlang ek ander moet ook vir my behandel soos enige ander mens behandel word. Ek wil nie hê hulle moet vir my kyk met daai aandag of my jammer kry nie. Um ja ek wil graag hê hulle moet lief wees vir my, dam liefde is die ding wat ek die meeste mis in my lewe in en dan dis wat ek wil hê vir my kind ook..." (Elna)

From the researcher:

"The research experience had an altering effect on me as a person, woman and mother. It will be difficult to elaborate on this, or to put all of my feelings into words, but certainly two words can capture some of it, gratefulness and hope. Firstly HOPE, hope for all women suffering from an illness such as AIDS, hope for better support and care, hope for a better quality of life for these women on all levels, and hope for a cure and a future. Secondly GRATEFULNESS, gratefulness for the life that I live that is not filled with such extreme pain and adversity, and gratefulness for all the big and small things in life that I so easily take for granted." (Elsa)

"Die navorsingservaring het 'n bepalende effek op my as persoon, vrou en ma gehad. Dit is moeilik om hieroor uit te brei, of om al my gevoelens in woorde uit te druk, maar sekerlik kan twee woorde van hierdie gevoelens weergee, dankbaarheid en hoop. Eerstens HOOP, hoop vir alle vroue wat ly aan 'n siekte soos VIGS, hoop vir beter ondersteuning en sorg, hoop vir 'n beter kwaliteit lewe vir hierdie vroue op alle vlakke, en hoop vir genesing en 'n toekoms. Tweedens DANKBAARHEID, dankbaarheid vir die lewe wat ek ly wat nie gevul is met sulke ekstreme pyn en swaarkry nie, en dankbaarheid vir al die klein en groot dinge in die lewe wat ek so maklik as vanselfsprekend aanvaar." (Elsa)

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Addendum A

The illness experience of HIV-infected women: a review of psychological studies

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1. Introduction

There is now broad consensus that AIDS, “plague of the millennium”, “health disaster of pandemic proportions”, is the greatest public health problem of our era (Treichler, 1999). The rate of HIV infection among heterosexual women is exceeding that of men worldwide, and there is evidence that women die more quickly once infected (Kimerling, Armistead & Forehand, 1999; UNAIDS/WHO, 2004; Whiteside & Sunter, 2000). It is thus evident that women are more at risk of being infected by the HI-virus and dying from AIDS, because of their biological make-up and various sociocultural factors. Many writers and researchers have emphasised that AIDS is increasingly afflicting low-income women who have little economic, political or social power (Gillman & Newman, 1996; Hackl, Somlai, Kelly, & Kalichman, 1997; Seidel, 1998).

Despite documented cases of AIDS in women from almost the beginning of the epidemic, AIDS was assumed by most of the medical and scientific community to be a “gay disease” and a “male disease”, assumed to be different from other sexually transmitted diseases (Treichler, 1999). Treichler (1999) stated that most studies of women with HIV/AIDS were explicitly justified by arguing that HIV incidence in women provided a general index to the heterosexual spread of the virus and that the purpose of identifying women at risk and preventing primary infection in them was to prevent cases of HIV/AIDS in their partners and children. This emphasised that there was no inherent concern for women as women. The women at risk were considered “not normal” and they included prostitutes, drug abusers, minority and poor women, and women in the Third World (Treichler, 1999).

Although the AIDS epidemic continues to disproportionately affect disadvantaged women with low socio-economic status, it is important to know that women of various ethnicities are being infected and affected by HIV/AIDS. Broun (1999) discussed cases of middle-to-upper-middle-class women being HIV-positive or having AIDS. According to her, the myth that “nice women don’t get AIDS” is perpetuated not just by the person, but also by physicians and other healthcare professionals. This contributes to the predicament that these women only get tested when the illness has progressed to a symptomatic stage.

Broun (1999) argued that if these women had been tested earlier on, they could have received prompt medical and prophylactic treatment. New research also affirms that lesbian women are equally at risk as others whenever bodily fluids are exchanged (Broun, 1999). Thus, women in general are at risk of contracting HIV/AIDS.

Factors contributing to higher HIV infection in women are the greater efficiency of male-to-female HIV transmission through sex and the younger age at initial infection for women (UNAIDS/WHO, 2004). Although the increased risk for women to get infected via sexual intercourse is related to female anatomy and physiology, various sociocultural factors, such as poverty, low-socio-economic status, violence and gender issues also contribute to this phenomenon (Ackermann & de Klerk, 2002; Gaskins, 1999; Morokoff, Mays & Coons, 1997). Transmission of the HI-virus in Third World countries was also ascribed to, inter alia, the practice of anal intercourse as a method of birth control, the use of unsterilised needles in clinics and hospitals, various practices of “native healers”, various “rituals”, circumcision in women, multiple households or marriages, and widespread prevalence of disease and malnutrition (Treichler, 1999). Thus, various biological, social, cultural and economic reasons contribute to the high numbers of women contracting HIV/AIDS.

Withell (2000) affirmed that in addition to their biological vulnerability to HIV infection, women in developing countries bear a double burden enforced by AIDS because of their subordinate position in society and the heavy burden of their care-providing roles. She stated further that in her study the effects of poverty were extensive and that it was aggravated by widowhood and the loss of the potential to work as the illness progressed. Servellen et al. (cited in Withell, 2000) found that poverty and fatigue in HIV-positive women are strongly correlated with socio-economic circumstances such as unemployment and dependent children, as well as depression.

A study carried out by Semple et al. (cited in Rose & Clark-Alexander, 1996) identified key stressors in the lives of women diagnosed with HIV/AIDS, which ranged from fatigue, insomnia, child and family concerns, marital and partner concerns, job-related and economic concerns to social-network concerns. The major concerns expressed by HIV-

infected women in the study conducted by Issiaka, Cartoux, Ky-Zerbo, Tiendrebeogo, Meda, Dabis and Van de Perre (2001) were health and healthcare. Peterson et al. (cited in Simoni & Ng, 2002) suggested that personally perceived health of HIV-infected women can be negatively influenced by inadequate social support networks and healthcare, maladaptive coping with stress and less effective immune system response.

Withell (2000) emphasised that HIV/AIDS is a chronic, unpredictable, life-threatening disease in which suffering is exacerbated by bereavement, stigma, poverty and other coexisting stresses. These unique psychosocial issues have an enormous personal and societal impact on HIV-infected women (Withell, 2000). Therefore disclosure, stigma, healthcare, poverty, and gender roles are all special concerns, problems and challenges for women with HIV/AIDS and healthcare providers.

2. Stigmatisation and disclosure

Stigmatisation and blaming often mark the HIV/AIDS discourses in Africa (Bunting, 2001; Grinstead, Gregorich, Choi & Coates, 2001; Haram, 2001; Leclerc-Madlala, 2001; Morrow, Costello & Boland, 2001; Withell, 2000). Stigma sets AIDS apart from other terminal diseases and the disease is defined as a "mark of shame or discredit" (Heath & Rodway, 1999, p.45). Cohan and Atwood (1994) stated that it would be hard to think of another disease that is associated with so much stigmatisation, that is, connected to stigmatised groups like homosexuals, drug users and prostitutes, sexually transmitted and deadly.

Grinstead et al. (2001) pointed out that higher levels of disclosure were reported in first-world countries like the United States and negative consequences were uncommon. In developing countries, however, research studies showed much lower rates of disclosure and more harmful outcomes after disclosure for women (Grinstead et al., 2001). According to Haram (2001), it is commonly acknowledged in most African countries that when men are infected, their wives are suspected of infidelity, but when women are infected they are assumed to have had multiple partners. "Men are simply susceptible to

the potentials of these actions, while women are held responsible for their consequences" (Weiss, cited in Haram, 2001, p.49). Bunting (cited in Leenerts and Magilvy, 2000) stated that women with HIV/AIDS are stigmatised in numerous ways, "women have been stigmatised for their gender, their sexuality, their minority status, and their poverty, as well as for their HIV-positive status" (p.69). According to Schneider (1992), women are commonly blamed for their pregnancies, abortions, sexually transmitted diseases, and prostitution.

A study conducted by Leclerc-Madlala (2001) also supports and supplements research from various parts of Africa which revealed that women are being blamed for the cause and spread of HIV/AIDS. She further stated that the current HIV/AIDS epidemic is adding new substance and a new dimension to a deep-rooted and possibly ancient symbolic construction of women-danger-disease. "The foundational assertion of AIDS symbolism is that women are both the source of HIV infection and the disseminators of AIDS illness and death" (Leclerc-Madlala, 2001, p.42).

According to Gaskins (1999), women delay seeking testing for HIV/AIDS because they are afraid of knowing the truth, the stigma attached to the illness and disclosure. Gaskins (1999) stated that there are special issues concerning disclosure for women that need to be recognised and studied, such as the reluctance to confide in healthcare workers and specific concerns regarding their children. Furthermore, if they tested positive for HIV they were anxious about telling others, how others would handle the information, and how their lives would be changed (Gaskins, 1999). In the study conducted by Leenerts and Magilvy (2000) women believed that telling others ruined their chances to be treated as normal human beings. They were apprehensive that telling would open up the possibility for HIV-related stigma and the social devaluation that accompanies stigmatisation (Leenerts & Magilvy, 2000). According to Hackl et al. (1997), women who share their HIV/AIDS diagnosis with family or friends risk stigmatisation (including reactions of fear, shock and blame), isolation (because of others' fears of casual transmission and the possibility of desertion), and potential loss of self-esteem (lack of confidence and self-blame). O'Hea, Sytsma, Copeland and Brantley (2001) stated that stigma might lead to a variety of

negative consequences such as social isolation, job termination, housing difficulty, and negligent care by medical professionals and caregivers.

Bunting (2001) pointed out that women with HIV and caregivers of people with HIV/AIDS, who are typically women, have their own particular sources of stigma and share a stigma by association. According to Bunting (2001) this continuing stigma associated with the illness is cited in several of the caregiver studies and it often adds to the work and despair of the caregiver by increasing anxiety and stress and by the process of isolating both the patient and caregiver from potential sources of support and comfort. Furthermore, in many instances the caregiver is HIV-infected herself.

Moneyham et al. (cited in Leenerts & Magilvy, 2000) stated that experiences of stigmatisation affect health outcomes including mental health and quality of life. According to Sowell, Moneyham and Aranda-Naranjo (1999), concerns about stigma, revealing one's HIV-status to others, and victimisation, may disrupt earlier caring and helpful relationships and prevent women with HIV/AIDS from utilising much needed sources of support. Therefore, stigma-related issues can add to psychological distress, loneliness, depression and an inability to employ needed support and services that promote effective coping. Gaskins (1999) emphasised that stigma and disclosure need to be addressed in HIV/AIDS care because of their effect on, inter alia, emotional distress, how women manage their illness and overall healthcare, and their quality of life in general.

3. Quality of life of women with HIV/AIDS

The harmful psychosocial impact of HIV/AIDS on quality of life has been well documented in the literature (Catz, Gore-Felton & McClure, 2002; Sarna, Van Servellen, Padilla & Brecht, 1999). According to Vosvick, Koopman, Gore-Felton, Thoresen, Krumboltz and Spiegel (2003), quality of life embraces many aspects of a person's well-being, including overall health, pain, physical functioning, social functioning, and role functioning and mental health. Quality-of-life studies focusing on women with HIV/AIDS have described a

number of variables which influence both the type and severity of disruptions as well as coping with everyday life. According to Sarna et al. (1999), HIV treatments, physical symptoms, psychological health and role performance have been linked to disturbances in quality of life.

Rose and Clark-Alexander (1996) stated that clinical characteristics of HIV disease have been directly related to a decline in quality of life. Patients with more advanced symptoms got lower quality-of-life scores than those with fewer symptoms (Wachtel et al., cited in Rose & Clark-Alexander, 1996). Ragsdale et al. (cited in Rose & Clark-Alexander, 1996) found that psychosocial aspects of life also had a fundamental influence on the quality of life of women with HIV/AIDS. According to Catz et al. (2000), higher levels of psychological distress have an adverse influence on quality of life and have been associated with poor treatment adherence and higher rates of risk behaviour for HIV transmission among HIV-infected people.

De Marco and Johnsen (2003) emphasised that the bio-psychosocial needs of women are unique and complex compared to those of male patients. They reported that women in their study struggled with isolation, low self-esteem, family and child concerns, housing, violence, substance addictions, different physical side effects from antiretroviral medications, as well as paralysing fears and uncertainties concerning their own lives and the future of their children. Thus, a range of bio-psychosocial issues, affecting quality of life, determine the health and well-being of women with HIV/AIDS. These major issues and clinical, psychological, and social concerns will be discussed in the following sections, with emphasis on the psychosocial concerns and needs of HIV-infected women.

4. Clinical issues

Symptoms in HIV illness can be caused by the HIV infection itself, by the side effects of medications and treatments or by the related opportunistic infections (Shumaker et al., cited in Hudson, Lee, & Portillo, 2003). The symptom experience in HIV/AIDS has been

documented in numerous research studies. Holzemer et al. (cited in Hudson et al., 2003) divided symptom problems into two clusters: 1) symptoms related to disease, inter alia, shortness of breath, fever, fatigue and weight loss, and 2) symptoms related to treatment, which included nausea and vomiting. In a study conducted by Henry et al. (cited in Hudson et al., 2003) it was found that the top five health problems for hospitalised AIDS patients were dyspnea (shortness of breath), fever, fatigue, nutritional problems and medication side effects.

There are sufficient data to show that women with HIV/AIDS first present for medical care with more advanced symptoms that rapidly progress, and have a shorter survival time than their male counterparts (Sowell et al., 1999). As a woman's immune system deteriorates, she may be living with multiple chronic illnesses. Unique symptom and clinical manifestations related to HIV/AIDS for women are physical presentations that involve the reproductive system, such as recurrent vaginal candidiasis which is common in HIV-infected women, as well as pelvic inflammatory disease and invasive cervical cancer (Gaskins, 1999; Sowell et al., 1999; Strebel, 1995).

In the study conducted by Breitbart (cited in Sarna et al., 1999), it was found that the women participants reported significantly higher pain intensity scores than the men participants. Fatigue was also more frequently reported by HIV-infected women and is commonly seen as a danger sign that progression of disease and disability are occurring (Rose & Clark-Alexander, cited in Hudson et al., 2003). Because most women with symptomatic HIV disease are low-income women with young children, parenting adds to the experience of higher morning fatigue (Lee et al., cited in Hudson et al., 2003). According to Hudson et al. (2003), the extent to which fatigue affects women's daytime activities and functional status, such as their ability to be employed, care for their home and children and actively involve themselves in their communities, has not been a focus of research.

According to Dodd et al. (cited in Hudson et al., 2003), physical symptoms can be distressful and frustrating for patients and caregivers because they often are not

acquainted with management approaches that would be appropriate, and because symptoms can be erratic owing to their dynamic and varying nature. Consequently, medical treatment and self-care are of great importance for women with HIV/AIDS in order to treat symptoms and prolong physical well-being.

4.1 Medical treatment and care

Sarna et al. (1999) stated that benefit from treatment is contingent upon early diagnosis and access to HIV-care services. These researchers pointed out that in the early phases of the HIV epidemic, few women were diagnosed, and information about illness presentation in women was partial. Because of the lack of data about HIV in women, it can be expected that women are more likely than men to be misdiagnosed, or to have a delay in diagnosis (Stevens, cited in Sarna et al., 1999).

Gaskins (1999), Haigney (cited in Cohan & Atwood, 1994) and Sowell et al. (1999) stated that late HIV diagnoses result in women obtaining medical intervention and care at later stages during the progression of the illness, and therefore they are sicker than men when they begin receiving treatment. Cohan and Atwood (1994) pointed out that, generally, women with AIDS have a shorter life expectancy than men. According to Hankins (cited in Heath & Rodway, 1999), if women with HIV/AIDS had access to needed healthcare, their rate of illness progression would not be worse than that of men. Therefore, the difficulties women with HIV/AIDS experience, particularly impoverished women of colour, with finding prompt and appropriate healthcare may affect their overall health status, quality and duration of life (Cu-Uvin et al., cited in Sarna et al., 1999).

The majority of disadvantaged groups and low-income women with HIV/AIDS in South Africa, as in the rest of the developing world, are not receiving adequate medical care and antiretroviral treatment (ART) for their illness. Although the South African government embarked on a national programme in 2004 to provide ART to all people who meet the criteria for eligibility, by September 2004 just over 11 000 of the 500 000 South Africans in

need of medication had been placed on treatment since the programme started in April 2004 (Brouard, 2005).

In South Africa, the dilemma of providing much needed antiretroviral treatment to low-income women and pregnant women has not been successfully addressed or solved. The Department of Health is lagging behind the timelines for providing these drugs. Geffen of the Treatment Action Campaign said that the delay is causing confusion, loss of dignity, suffering and death (cited in Smetherham, 2004).

In the study conducted by Kalichman, Graham, Luke & Austin (2002), women who were not receiving ART were less likely to know their viral load and CD4 (t-lymphocyte cell) count, markers for personal awareness of one's health status. In addition, the women who were untreated were significantly less likely to believe they were receiving good healthcare and were significantly less likely to view their healthcare as the best available. They were also less likely to indicate that their doctor answers their questions, asks their opinions, and explains their condition to them (Kallichman et al., 2002).

Furthermore, some women are cautious of taking medication such as ART. According to Sowell et al. (1999), a factor that can impact the course of HIV/AIDS in women is their acceptance and use of prescribed drug treatments. She further stated that in underprivileged women, the decision to accept antiretroviral drugs as treatment for HIV/AIDS could be based on cultural considerations, such as a customs of self-care or folk healers. Sowell et al. (1999) stated that there is evidence to suggest that some HIV-infected women are unwilling to take antiretroviral drugs because of apprehension about their effectiveness and side effects and beliefs that the drugs are experimental.

According to Gaskins (1999), the most trusted source of information about HIV/AIDS and motivational factor for medical treatment was contact with other women infected with HIV. Furthermore, research showed that women who have a positive trusting relationship with their healthcare providers were most likely to accept treatment or take antiretroviral medication (Gaskins, 1999; Seals et al., cited in Sowell et al., 1999). Gaskins (1999)

pointed out that research studies underscore the many challenges involved when caring for and treating HIV-infected women. According to Gaskins (1999), healthcare workers need to be educated and encouraged to identify HIV-infected women and offer appropriate medical treatment as early as possible.

4.2 Summary

In the literature, it is clear that the physical symptoms caused by the HIV infection itself, by the side effects of medications and treatments or by the related opportunistic infections, have a detrimental effect on a woman's general well-being and functioning. It is also clear that women, especially disadvantaged women of colour, do not receive the treatment and care they need. Thus, untreated symptoms can cause women to fall ill more rapidly and this can lead to early death. Furthermore, physical distress and pain are associated with emotional distress and a decline in psychosocial functioning. In the literature it is emphasised that besides physical care and treatment, women in particular have specific psychosocial needs in relation to AIDS that need to be addressed.

5. Psychosocial issues

Although medical treatment and symptom management are of the utmost importance for women with HIV/AIDS, Kalichman et al. (2002) and Sowell et al. (1999) argued that interventions focusing only on one aspect of the HIV/AIDS experience have limited usefulness. According to these writers, emotional, social and spiritual issues can enhance or hamper the physical management of the illness, just as physical well-being can influence psychosocial functioning.

Sowell et al. (1999) explained that during the various stages of the illness, issues relating to psychological, social and spiritual needs are apparent, and during periods when symptoms are not present or manageable, these issues may actually be of greater

importance than the physical health issues associated with the illness. Martinez, Israelski, Walker and Koopman (2002) emphasised that women with HIV/AIDS experience a wide range of social, emotional and psychiatric problems that are accompanied by numerous personal and social losses. Withell (2000) identified bereavements, social losses (especially those associated with widowhood as well as being rejected by family and friends), loneliness, poor self-esteem, sexual limitations and loss of direction (future plans) as important personal and social losses.

According to Brown (1999), a woman's experiences of being HIV-infected are essentially determined by her individual psychological make-up, such as premorbid mental health, sexual orientation, substance abuse, self-esteem, religion and spiritual beliefs, as well as her social circumstances, and support from important others, family and the community. Therefore, these issues should all be taken into consideration when studying the illness experience of women with HIV/AIDS.

5.1 Psychological distress

Throughout the literature, high levels of psychological distress among HIV-infected populations have been documented. The initial impact of an HIV-diagnosis is commonly characterised by shock, disbelief, fear and numbness, and feelings of devastation that may progress to suicidal thoughts (Stevens et al., cited in Withell, 2000). Catz et al. (2002) stated that a person's HIV-positive diagnosis is often accompanied by depression, suicidal ideation, suicide attempts, anxiety, loneliness, and other somatic and psychological symptoms of distress. Heath and Rodway (1999) pointed out that frequent themes in the literature concerning the emotional impact of HIV infection are feelings of betrayal, failure, insufficiency, guilt and shame, depression, anger, low self-esteem, uncertainty about the course of the illness, fear of rejection, fear of death, feelings of loss of power and control, and suicidal ideation. According to Heath and Rodway (1999), some writers describe certain feelings as being more prevalent at different times in the illness process, such as shock at the time of diagnosis and spiritual/existential issues at a later phase. Other

writers stated that some women face spiritual/existential issues immediately after diagnosis because of the connection between AIDS and premature death (Christ et al., cited in Heath & Rodway, 1999).

Withell (2000) pointed out that the impact and devastation of and emotions aroused by a positive test result seem to be comparable across cultures and correspondent to those portrayed in the literature. However, Catz et al. (2002), Sarna et al. (1999) and Simoni and Ng (2000) pointed out that psychological distress could be more severe for women than for men with HIV/AIDS, especially for impoverished women of colour. According to Schrimshaw (2003), HIV-infected women may experience major problems adjusting to their illness. Feelings of shame and embarrassment are common for women infected with HIV. Although some men may experience this, it seems that women have introjected social views and feel more ashamed of their status (Broun, 1999). Broun (1999) stated that despite how women became infected, many feel a great deal of shame, guilt and loneliness.

Furthermore, women's psychological response to HIV infection, including the trauma of a positive diagnosis, may have implications for illness progression and survival (Earl et al., cited in Kaplan, Marks & Mertens, 1997). Kaplan et al. (1997) discussed an emerging body of literature in psychoneuro-immunology which suggests that psychological phenomena such as depressed mood, hopelessness and fatalism, anxiety and loneliness may accelerate the pace at which HIV progresses. Long-term studies confirmed that the level of psychological distress experienced by HIV-infected individuals was directly related to the rate of illness progression over a five-year period (Burach, cited in Rose & Clark-Alexander, 1996). These findings emphasise that a major focus of care for women with HIV/AIDS should be on the psychological aspects of the illness and not only on the physical treatment of illness symptoms.

In the literature, loneliness, anxiety, and depression were described as the most common psychological reactions following a diagnosis of HIV or AIDS (Faithfull, 1997; Gillman & Newman, 1996; Jue, 1994; Kaplan et al., 1997; Kelly & Lawrence, 1988; Kiemle, 1994;

Linn, Poku, Cain, Holzapfel & Crawford, 1995). Therefore, loneliness, anxiety and depression will be discussed briefly in the following sections.

5.1.1 Loneliness

Loneliness associated with mourning, a depressed mood and anxiety usually results when the diagnosed person withdraws from others out of fear of rejection, or when existing social support networks withdraw from the person following her HIV-diagnosis. Weiss, the leading spokesperson for an interactionist approach to loneliness, stated that loneliness is caused not by being alone but by being without some definite needed and meaningful relationship, or set of relationships, or connectedness with a coherent and supportive community (Peplau & Perlman, 1982; Weiss, 1973). Weiss (1973) emphasised that loneliness arises when one's social interactions are deficient in supplying crucial social requirements such as attachment, guidance and a sense of worth. According to him there are two types of loneliness, emotional isolation and social isolation. The first is produced by the absence of a close emotional attachment or a lack of intimate others, and the second by the absence of an accessible and engaging social and community network. Loneliness arising from social isolation is the situation of the individual without sufficient links to and support from the surrounding community. According to Weiss (1973), anything that leads to loss of contact with those who share one's concerns, like social stigmatisation and prejudice, may give rise to social isolation. Dukes and Denny (1995) emphasised that a fatal illness such as AIDS, which is accompanied by much suffering, creates greater perceived danger of contact and increases social prejudice and distance.

On the basis of their research, Rokach and Brock (1998) proposed a general model for the perceived causes of loneliness, which consists of five factors: 1) Personal inadequacies (17% of the variance), which include items that describe enduring personal characteristics or previous aversive experiences associated with low self-esteem, mistrust, fear of intimacy and feeling socially ill at ease; 2) Developmental deficits (5%) describe possible developmental and familial antecedents of adult loneliness such as growing up in an inadequate or

dysfunctional home that would be characterised by emotionally distanced or rejecting parents or psychological or physical abuse; 3) Unfulfilling intimate relationships (4%) describe the effect of disappointing, hurtful or emotionally abusive intimate relationships or friendships on the development of loneliness; 4) Relocation and significant separations (4%) describe the changes and often loss of important relationships that occur as a consequence of mobility, relocation or death; 5) Social marginality (3%) describes the social rejection and distancing which criminals, the unemployed and chronically ill persons commonly experience (p. 1068).

The results of a study conducted by DeBerard and Kleinknecht (1995) proposed that both the intensity and duration of loneliness are predictive of stress symptomatology, such as depression, anxiety, anger, and somatic complaints; however, duration of loneliness appears to be a significantly better predictor than intensity of loneliness. Friedman and Katz (cited in De Gouveia, 1984) suggested that prolonged or chronic loneliness or repeated rejection, as experienced by HIV-infected persons, leads to self-blame and finally to depression.

According to Rokach and Brock (1998), a lonely person is generally regarded as undesirable. Because of the stigma attached to being lonely, most lonely people do not reveal, let alone discuss, their actual thoughts and feelings while they are undergoing the experience. This may lead to ineffective coping mechanisms, such as substance abuse. Thus a person diagnosed with HIV or AIDS will not easily experience common group cohesiveness or be able to share emotions and thoughts regarding his or her diagnosis with important others, owing to stigmatisation and fear of rejection. This interpersonal estrangement can precipitate loneliness that may lead to the development of physical, psychological and behavioural problems and conditions such as depression and anxiety (Rokach & Brock, 1998). Consequently, a person with HIV/AIDS could experience severe emotional distress and psychological symptoms, because of the stigmatisation attached to both the illness and his or her state of loneliness.

Yalom (1995), a well-known group therapist who has led many groups of patients who all had some advanced form of cancer, stated the following: “I was repeatedly struck by the

realization that, in the face of death, we dread not so much nonbeing or nothingness but the accompanying utter loneliness" (p. 21). According to him, dying patients may often be haunted by interpersonal concerns of being abandoned, even shunned, by the world of the living.

Derlega and Margulis (cited in Peplau & Perlman, 1982) illustrated how patients with terminal conditions face terrible uncertainties associated with their illness. Patients who seek to clarify their feelings may become isolated and lonely, because of their own and others' inability to talk about the illness. They may fear that others would reject them if they discuss their illness. According to Derlega and Margulis (cited in Peplau & Perlman, 1982), health professionals may also avoid talking to patients about their illness on account of their own anxieties, which in turn makes it even more difficult for patients to talk about their problems. The absence of an appropriate person with whom to share their emotions and who will protect their intimate disclosures may lead to interpersonal estrangement and loneliness. Torres (cited in Sherr, 1995) compared the Kübler-Ross grief model in AIDS and cancer patients and found that people with AIDS became significantly more depressed and lonely than those with cancer. People with AIDS needed to talk about their losses while the cancer respondents analysed their grief. According to Torres (cited in Sherr, 1995), people with AIDS tended to indicate a greater need for family and peer support, but because of stigmatisation and fear of rejection this need was rarely satisfied. Consequently, this may lead to further emotional and social isolation.

According to Faithfull (1997), the grief observed in HIV-infected persons compares well with a typically pathological or abnormal grief reaction, which can enhance a depressive mood, anxiety, and loneliness. Loneliness most probably exacerbates HIV-infected women's emotional desolation and pain. The widespread prevalence of loneliness among people with life-threatening illnesses such as AIDS and the negative social consequences it has, indicate that further research is needed on ways to detect and support those who are lonely as a result of such a diagnosis.

5.1.2 Anxiety and trauma

Most women experience the time of an HIV-diagnosis as very traumatic because of the fatality of the illness, as well as the stigma attached to it. In the study done by Withell (2000), the women participants described their emotions at the time of diagnosis as feeling shocked, going mad or being dumbstruck, especially when they felt physically healthy. Leenerts and Magilvy (2000) stated that fear and panic were common responses for women at the time of diagnosis and that many described it as traumatic. According to Herman (1992), a traumatic event is extraordinary, because it overwhelms the ordinary human adaptations to life. Unlike commonplace misfortunes, traumatic events generally involve threats to life or bodily integrity, or being exposed to the possibility of dying (Herman, 1992). She stated further that a traumatic event confronts a person with extreme feelings of helplessness, fear, loss of control, and threat of annihilation.

Apart from the trauma and shock at the time of diagnosis, many poor women with HIV/AIDS are traumatised in their daily lives because of violence, domestic and sexual abuse. Brady, Gallagher, Berger and Vega (2002) and Martinez et al. (2002) stated that the high incidence of trauma in the lives of disadvantaged women with HIV/AIDS has enormous implications for the assessment, diagnosis and treatment of female patients. According to Brady et al. (2002), Martinez et al. (2002) and Simoni and Ng (2000) there is enough evidence to show that traumatic life experiences such as abuse and victimisation are highly prevalent in women with HIV/AIDS. As a consequence these women are at much greater risk for psychological distress, such as anxiety, depression and loneliness, or for being diagnosed with a psychiatric disorder. According to Gold et al. (cited in Simoni & Ng, 2000), many abused women with HIV/AIDS report more frequent and longer durations of depression and anxiety compared to those without histories of trauma.

Brady et al. (2002) stated that histories of abuse among women with HIV/AIDS often lead to the development of poor self-care skills, low self-esteem, passive suicidal behaviours such as non-compliance with medical treatments, and substance abuse. These writers anticipated that significant numbers of women with HIV/AIDS with a trauma history meet

the criteria for post-traumatic stress disorder (PTSD) or are experiencing PTSD-related symptoms. According to Martinez et al. (2002), applying the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders) criteria, an HIV-diagnosis in itself can be a potential trigger for PTSD. Martinez et al. (2002) reported that nearly two-thirds of the HIV-positive women participants in their study were evaluated as likely to have partial or full PTSD, which is far greater than the prevalence rate of current PTSD in the general population of women. Also significant was the high numbers of traumatic life events experienced in this sample of HIV-positive women, such as having had an abortion or miscarriage, having serious financial problems and being exposed to violence, sexual, physical and emotional abuse or neglect in the home.

In addition, exposure to physical and sexual abuse is frequently associated with psychiatric illnesses such as anxiety disorders or depression, as well as the development of substance abuse disorders (Martinez et al., 2002). According to Catz et al. (2002) the most frequent psychiatric diagnosis associated with HIV is an adjustment disorder with features of anxious, depressed or mixed mood. Lindegger and Wood (1995) reported studies which have found that many people with HIV infection experience levels of anxiety and depression that are severe enough to warrant diagnoses of adjustment disorders, anxiety disorders and major depressive episodes.

Sowell et al. (1999) stated that it is of the utmost importance that future research studies document the incidence of interpersonal violence experienced by women with HIV/AIDS as well as the impact of such violence on the psychological well-being of HIV-infected women. Brady et al. (2002) emphasised that clinicians and other health professionals working with women at risk for or infected with HIV need to better assess, diagnose, and treat trauma-associated disorders and anxiety symptoms, which can have an important influence on health-related behaviours, including sexual risk behaviours, substance use, self-care practices and medication compliance.

It is clear from the above literature that many HIV-infected women experience anxiety and depressive symptoms concurrently. However, in most studies depression seems to be a more common condition that warrants serious attention.

5.1.3 Depression

In the literature, depressive symptoms are one of the most frequent groups of distress responses described by HIV-infected individuals. Kelly et al. (cited in Boonpongmanee, Zauszniewski & Morris, 2003) affirmed that depression is the first response that is likely to occur after an HIV-diagnosis. According to Sowell et al. (1999), HIV-positive individuals have been found to report significantly more depressive symptoms than both HIV-negative control groups and comparison samples from the general population. In addition, the suicide rate among HIV-infected males has been reported to be significantly higher than that found in control groups of non-infected males and that reported for demographically comparable samples of men in the general population (Sowell et al., 1999). According to Heath and Rodway (1999), recent research indicated that the risk of suicide among people with HIV/AIDS was 36 times that of the general population.

Penzak et al. (cited in Catz et al., 2002) estimated the lifetime prevalence of major depression among persons living with HIV at 22% to 45%, whereas lifetime depression occurs in about 17% of the general population, according to data from the National Comorbidity Survey. They also found that rates of depression and anxiety disorders were higher among women than among men living with HIV/AIDS. Catz et al. (2002), Kaplan et al. (1997), Morrow et al. (2001), Richardson, Barkan, Cohen, Back, FitzGerald, Feldman, et al. (2001) as well as Sowell et al. (1999) stated that even though mainstream research on depression within the context of HIV/AIDS has focused on men, existing evidence reveals that women with HIV/AIDS are at particular risk.

A recent epidemiological study of HIV-infected women identified 77% with chronic or intermittent symptoms of clinical depression (Ickovics et al., cited in Schrimshaw, 2003).

Simoni et al. (cited in Schrimshaw, 2003) also identified similarly high rates (60 – 61%) of probable clinical depression among women living with HIV/AIDS. According to Catz et al. (2002) and Murphy, Marelich, Dello Stritto, Swendeman and Witkin (2002), the differences in distress levels between women and men are ascribed to discrepancies in contextual and sociocultural issues, such as poverty, childcare responsibilities, responsibilities of caring for others infected with HIV, and the stigma and social isolation that women living with HIV experience. In the study conducted by Bunting (cited in Bunting, 2001), stigma was a primary predictor of depression in the caregivers, who were often HIV-infected themselves.

Olley, Gxamza, Seedat, Stein and Reuter (2003) assessed psychiatric morbidity of HIV-infected patients, who mostly were women, with the MINI International Neuropsychiatry Interview, a brief structured interview that allows diagnoses of major psychiatric disorders. Their descriptive analysis of the MINI showed the prevalence of current depression as 38.7%; lifetime depression 19.1%; dysthymia 28.0%; suicidality 9.7%; hypomania 2.2%; panic disorder 7.5%; social anxiety disorder 6.5%; posttraumatic stress disorder 12.9%, and generalised anxiety disorder 9.7%. According to Olley et al. (2003) these rates of depression were very similar to those seen in both the developed world (48%) as well as those described in the more limited literature from the developing world, where rates of 46% have been reported.

Olley et al. (2003) stated that psychopathology associated with HIV/AIDS disease may reflect the affect of finding out that one suffers from a stigmatised illness, or suffering from physical/medical symptoms, or the consequences of losing relationships as a result of the diagnosis. According to these writers certain psychiatric disorders may also be secondary to neuropathology caused by HIV/AIDS itself. A study conducted by Skolnick (2002) found that depressive and anxiety symptoms were significantly associated with higher HI-viral load levels and that major depression was associated with significantly lower natural killer cell activity. Therefore depression may have a negative impact on natural immunity and quicken illness progression in women (Skolnick, 2002).

Sowell et al. (1999) emphasised that depressive symptoms are a particularly important issue in HIV/AIDS owing to the correlation between depressive symptoms and health-related outcomes. Recent data from the HIV Epidemiological Research Study in the United States, a prospective examination of the natural course of HIV in women, documented depression in up to 62% of HIV-positive women participants (Morrow et al., 2001). Morrow et al. (2001) stated that depression scores over time in this four-and-a-half-year study were significantly connected to CD4 (t-lymphocyte cell) count and viral load and to HIV-related symptoms. Results obtained from a study by Richardson et al. (2001) correlated with findings from previous studies indicating depressive symptoms being associated with progressive disease and disease symptoms. According to Richardson et al. (2001) depression is exacerbated by the experience of symptoms and debilitating disease and most probably by learning that these illnesses are "AIDS defining" (p.106). In the literature it is emphasised that health professionals should inquire about HIV/AIDS patients' psychiatric symptoms and psychological distress, so that these symptoms can be treated together with physical symptoms.

Schrimshaw (2003), like many other writers, emphasised that the high levels of depressive symptoms among women living with HIV/AIDS show an urgent need for health professionals to identify issues associated with their adjustment and coping with their illness, in order that effective interventions can be designed and put into practice.

5.1.4 Depression and grief

Sherr (1995) stated that grief is not a single concept but meanders in many forms through the course of an illness such as AIDS, therefore the effects of grief are cumulative and add disproportionately to the emotional burden. Grief is a group of intense emotional, cognitive and physical symptoms experienced when a person is diagnosed with a terminal illness such as AIDS. Mullan, Pearlin and Skaff (2000) defined grief as "the complicated set of emotional and cognitive responses that accompany loss" (p.149). Although grief includes a variety of emotions, the principal emotion associated with grief is depression.

According to Mullan et al. (2000), it may be a low-grade dysphoria in people who continue to function in their normal social roles but who live their lives in an emotional valley, or it may be more severe, immobilising the person psychologically. According to Faithfull (1997), the grief observed in HIV-infected persons compares well with a typically pathological or abnormal grief reaction, which can enhance a depressive mood, anxiety, and loneliness.

A process of grief towards "acceptance" of death has been described by Elizabeth Kübler-Ross, based on her interviews with hundreds of terminally ill adults and children (Bee, 1994). She suggested five stages or reactions of a terminally ill patient to impending death: shock, denial, anger, bargaining, depression, and acceptance (Torres, cited in Sherr, 1995). According to Kübler-Ross (cited in Bee, 1994), denial as first reaction gives the patient a period of time in which to marshal other strategies of coping with the shock of the diagnosis. Thereafter, anger may be a response to the verdict of death but also to the typically dependent and helpless position of a patient. Kübler-Ross (cited in Bee, 1994) stated that the third reaction, bargaining with health practitioners and with God, only works for a certain period of time. As the illness progresses and the signs of the body's decline become more obvious, patients typically become depressed.

Bee (1994) described the depressive stage as mourning for the loss of relationships as well as of one's own life. Often the dying person sinks into despair that may last for a prolonged period of time. Kübler-Ross (cited in Bee, 1994) argued that this depression is part of the preparation for the last step, acceptance. According to her the dying person must grieve for, and then let go of, all the things of the world, so that acceptance of death can occur. According to Kübler-Ross's theory, acceptance as final stage is a peaceful understanding, a readiness for death. Kübler-Ross (cited in Bee, 1994) believed that a current of hope ran through all of these stages: "Patients hope for a new form of therapy, a new drug, a miraculous cure. And patients hope that they can die 'well', without too much pain and with some acceptance" (p.462).

Torres (cited in Sherr, 1995) argued that when comparing the experiences of terminally ill or dying patients it is important to keep in mind that patients seldom follow a typical series of responses that can be clearly identified as suggested by Kübler-Ross, and that the time period can also differ drastically. According to Torres (cited in Sherr, 1995), no established sequence or time period is applicable to all terminally ill patients. Sherr (1995) stated that theories that outline stages and phases in the grieving process can be useful in describing and defining the range and extent of emotional experiences, but are limited when invoked literally without the flexibility to adjust to and accommodate individual variation.

Bee (1994) affirmed that many clinicians and researchers who have attempted to study the process of dying more systematically have not found that all dying patients exhibit these five reactions or emotions, let alone in specific order. According to her there is not sufficient support for the notion that all or even most dying adults move toward emotional disengagement or acceptance. Edwin Shneidman (cited in Bee, 1994), a major theorist and clinician in the field of "thanatology" (the study of dying) said the following:

> I reject the notion that human beings, as they die, are somehow marched in lock step through a series of stages of the dying process. On the contrary, in working with dying persons, I see a wide panoply of human feelings and emotions, of various human needs, and a broad selection of psychological defences and manoeuvres - a few of these in some people, dozens in others – experienced in an impressive variety of ways. (p.463)

Thus, instead of each person following a series of five fixed stages, each person moves back and forth, in and out of a complex set of emotions and defences.

In the case of HIV/AIDS, the grief process can be even more complex and problematic, because of the illness being stigmatised and the person infected with the illness condemned and rejected by society. It is generally accepted that HIV/AIDS is a much more stigmatised and condemned illness than cancer. Kübler-Ross's model, as many other theories on the dying process, was based on the reactions and experiences of mainly

middle-class cancer patients (Torres, cited in Sherr, 1995). Sherr (1995) pointed out that many research studies found that people with HIV/AIDS become significantly more depressed than those with cancer, and that anxieties related to death were significantly greater for the former group. Thus, as has been repeatedly emphasised in the literature, the stigma attached to HIV/AIDS as well as the social circumstances of being disadvantaged and poor, could most likely have a negative influence on the grief process, the degree of depressive symptomatology and the overall psychological distress experienced by women with HIV/AIDS.

5.1.5 Summary

In the literature, it is emphasised that although women diagnosed with HIV/AIDS experience some of the same psychological distress as men with the illness, they have unique psychological concerns and needs that warrant special treatment and support. Psychological distress such as depression, anxiety and loneliness has been identified as particularly troublesome for HIV-infected, low-income single mothers (Rokach & Brock, 1998; Sowell et al., 1999). Thus, the potential widespread occurrence of psychological distress and symptomatology among disadvantaged women with HIV/AIDS supports the urgent need for mental healthcare and social service programmes that focus on the identification and treatment of these symptoms.

5.2 Social issues

Lorber (1997) pointed out that in societies where women's social status is very low, their life expectancy is less than in industrialised countries. Social factors that have a detrimental influence on women's health status are, inter alia, poor nutrition, complications of frequent child-bearing and sexually transmitted diseases because of a lack of power to demand abstinence, prevention or protection, and limited and restricted access to modern healthcare. Kimerling et al. (1999) and Sowell et al. (1999) confirmed that evidence

accumulated up till now indicates that where women are concerned, HIV/AIDS is mainly an epidemic of the disadvantaged. Women with HIV/AIDS usually live in poverty and may have chaotic lifestyles as a result of homelessness, substance abuse, and violent relationships (Sowell et al., 1999). These women frequently are of minority status and single heads of households with young dependent children. Braithwaite and Lythcott (cited in Cohan & Atwood, 1994) stated the following:

> Poverty and powerlessness create circumstances in people's lives that predispose them to the highest indexes of social dysfunction, the highest indexes of morbidity and mortality, the lowest access to primary care, and little or no access to primary prevention programs. Poverty of the spirit and of resources remains the antecedent risk factor of preventable disease. (p.7)

Leenerts and Magilvy (2000) declared that the sense of self in low-income HIV-positive women is portrayed in the literature as fragile and socially constructed in ways that make them vulnerable to poor physical and mental health. Recurring themes in the literature concerning their social circumstances indicate why loss of self and psychological conditions such as depression may well occur in low-income HIV-positive women:

1. Worries about daily survival (including care of children), job loss and economic worries;
2. Fears of domestic violence;
3. Social oppression in gender roles and caregiving;
4. Poor self-esteem, often attributed to childhood abuse and family dysfunction (at the adult level manifesting itself in substance abuse);
5. Difficulty accessing healthcare resources (problems in getting a diagnosis and receiving quality care);
6. Self-neglect, self-sacrifice, and silence;
7. The relationship of economic dependence to decisions about sexual practices, including prostitution;
8. Social structure changes that impact on income and health, such as welfare grants;

9. Ethnic and social oppression resulting in homelessness, welfare bureaucracy, and lack of health insurance and care. (Berer et al. and Rudd et al., cited in Leenerts & Magilvy, 2000, p.69)

According to Sowell et al. (1999), the lives of HIV-infected women are characterised by numerous unmet basic needs, making it difficult, if not impossible, to effectively treat their biological disease without confronting the negative socio-economic factors influencing their daily lives. Certain of these factors impacting the lives and functioning of HIV-infected women will be discussed in the next sections.

5.2.1 Gender, power and economic resources

Sowell et al. (1999) stated that despite the predisposition of health practitioners to extrapolate what is known about HIV-infected men to women with the illness, there is growing acknowledgment that women's experiences of the illness are different from men's, owing primarily to the position and social status of women in our society. According to Strebel (1993), the complexity of the AIDS situation in South Africa is compounded by discourses of gender and power:

> Women are positioned and position themselves as responsible for prevention of infection: for themselves, their children and their partners. They are also then by implication responsible for the spread of the virus. As a result, they should do something, it is incumbent on them to take action to curb the spread of the virus and to care for those infected. However, on the other hand, through the discourse of gendered power relations, they are seen as dependent on men, lacking control over their lives, and so unable to insist on condom use, abstinence or monogamy of male partners: in other words they can't do anything. (p. 195-196)

The above demonstrates a central paradox within gendered power relations that has major implications for understanding and addressing the problem of AIDS for women in South Africa.

Ackermann and De Klerk (2002) and Sowell et al. (1999) argued that the restrictions and limits of power, control and economic resources and the continuing dependency of women in our society are factors that not only contribute to the HIV/AIDS risk of certain groups of women, but also impact how women manage the illness. According to Heath and Rodway (1999), research studies that focused exclusively on women's psychosocial issues and AIDS found that power and control are central themes. They stated further that these themes traverse the societal and personal context and are also central in the areas of AIDS transmission, education on safe sexual practices and healthcare.

According to Cohan and Atwood (1994), a failure to acknowledge the "power differential" in many intimate relationships, which may increase women's exposure to HIV, is a failure to consider the cultural, social and economic imperatives that shape their lives (p.8). These writers stated further that women who depend on their partners for financial support may be reluctant to question a partner's past sexual experience or drug use if they believe such an inquiry might jeopardise the relationship. Gillespie (cited in Cohan & Atwood, 1994) reported that so many of the attitudes about women's worth and place and men's rights that permeate societies make successful prevention campaigns and adequate healthcare extremely difficult to achieve. According to Cohan and Atwood (1994) the health of women may, in addition, be jeopardised by public policies that presume infected women can be encouraged to reveal their positive HIV-status to husbands or intimate partners, even with the stigmatisation and blaming they experience.

According to Leclerc-Madlala (2000) and McDonnel and Gielen (2003), women's fear of potential violence affects their willingness or ability to broach the topic of using condoms with sexual partners. Women's difficulty in negotiating safer sex, being HIV-infected or not, is thus mainly due to their lack of power in interpersonal relationships and difficulty talking openly to their partners, as well as being financially dependent on their partners. According to Broun (1999), many HIV-infected women practise unsafe sex with their infected partner for the above reasons. Broun (1999) warned that certain specific viruses (i.e. cytomegalovirus) could be passed on, as can more virulent strains of HIV.

According to Kimerling et al. (1999), acknowledging and challenging the social context, in terms of gendered power relations and economic dependence of HIV-infected women, is of the utmost importance. In the lives of many women with HIV/AIDS gendered power relations relate to their experience of interpersonal violence. Therefore, the role of gendered power relations and interpersonal violence in the transmission of HIV infection and re-infection, as well as the influence it has on the psychosocial functioning of women with HIV/AIDS, needs to be confronted and challenged in research, prevention, and healthcare programmes for women.

5.2.2 Violence, poverty and substance abuse

Sowell et al. (1999) stated that a key social factor affecting the health and well-being of women with HIV/AIDS is their experience of interpersonal violence. According to Kimerling et al. (1999), the association between victimisation and adverse psychological symptoms as well as poorer physical functioning is increasingly cited in the literature focusing on women and AIDS. A study conducted by the University of Witwatersrand revealed that more than 60% of South African women are regularly beaten by boyfriends and husbands (cited in Ackermann & De Klerk et al., 2002). Grinstead et al. (2001) stated that high levels of violence against women in Africa have frequently been reported in the literature, and have suggested a strong linkage between violence and HIV infection.

Kimerling et al. (1999) emphasised that existing prevention interventions for women that primarily target only safe-sex skills and behaviours are failing to take into account the social context of HIV infection. Previous studies conducted by Kalichman et al. (2002) as well as Wyatt (cited in Kimerling et al., 1999) also affirmed that this context is one where violent victimisation is common and non-consensual sexual activity takes place. Consequently, violence may increase women's risk to get infected or re-infected with HIV. Furthermore, psychological and behavioural correlates of victimisation, such as anxiety and depression, may further weaken women's ability to negotiate sexual encounters (Johnson & Harlow, cited in Kimerling et al., 1999).

According to De Marco and Johnson (2003), Martinez et al. (2003) and Sowell et al. (1999) there is reason to believe that women with a higher risk for HIV infection or re-infection may also be at risk for psychological, physical and sexual abuse. These writers explained further that women with a history of child abuse, being involved with drugs or alcohol, and exchanging sex for money or other resources have been associated with HIV infection. They argued that since these factors are also recognised as risk factors for domestic violence, women who are dual sufferers of HIV disease and domestic violence may be exceptionally vulnerable to continued abuse, because they are frequently economically reliant on their abusive husband or partner.

McDonnell and Gielen (2003) stated that a partner's drug and alcohol use has been implicated as a possible reason behind the increased injury to women as a result of domestic violence. According to McDonnell et al. (2003), the stigmatising aspects of HIV/AIDS and the predisposition to blame the victim may also add to the risk for violence. Seals (cited in Sowell et al., 1999) pointed out that the related epidemics of violence, poverty, substance use and HIV infection make HIV/AIDS treatment and intervention even more problematic.

According to Kimerling et al. (1999), screening for victimisation in HIV patients may assist to identify women at risk for poorer prognoses who may benefit from preventative interventions, programmes targeting increased medical compliance, healthcare and substance abuse, as well as extensive psychological treatment. Consequently addressing the effects of victimisation may also enhance quality-of-life interventions and overall healthcare for HIV-infected women and mothers.

5.2.3 Women as caregivers

In the literature it is emphasised that women's traditional role as caregiver in society is a major issue impacting women living with HIV/AIDS. Although women with HIV/AIDS have

been disregarded in many of the studies and policy development in respect of AIDS, there has been even less focus on how HIV/AIDS affects women in their role as caregivers to their families and their status in their communities (Cohan & Atwood, 1994). Research studies indicated that HIV-positive women are particularly distressed by responsibilities and demands placed on them by family members and that many women reported greater symptoms of psychological distress and substance use (Murphy et al., 2002). Hackl et al. (1997) found that all the HIV-infected caregiving women in their study revealed evidence of clinical depression. These writers stated further that traditional caregiving responsibilities of HIV-infected women are often complicated by lack of social support and feelings of grief and loss accompanying their own terminal illness. Cohan and Atwood (1994) and Murphy et al. (2002) accentuated that limited social support, restricted economic resources, difficulty accessing healthcare services, housing needs, and physical and emotional fatigue are the hard and complex facets of the lives of most women who are caring for family members with HIV/AIDS.

Boyle et al. (1999) and Sowell et al. (1999) argued that because of the demands of their roles as mother, spouse, and caregivers of other family members and friends, women with HIV/AIDS often view their own health problems and needs as secondary to the needs of others for whom they are responsible. Consequently, these women's own needs are the least satisfied. Cohan and Atwood (1994) confirmed that when women are motivated to make their own health their primary concern, most of them experience conflict between concern for themselves and their roles as nurturers (Haigney, cited in Cohan & Atwood, 1994). Malcolm, Ng, Rosen and Stone (2003) found that HIV-infected women who did not adhere well to antiretroviral therapy, did not seem to focus on maintaining a good quality of life for themselves. For these women, being available to care for their children and/or spouses was of much greater importance.

5.2.3.1 Special concerns regarding children

Recent studies of HIV-positive women have shown that children were the central forces in their lives, giving meaning to their lives (Andrew et al., cited in Rose & Clark-Alexander, 1996). Many studies have found that women with HIV/AIDS are extremely worried about the care and welfare of their infected and uninfected children (Hackl et al., 1997; Richardson et al., 2001; Rose & Clark-Alexander, 1996). According to Forsyth (cited in Murphy et al., 2002), approximately 75% of women with HIV have an average of 2.6 children. Recent data indicated that large numbers of women that would be infected with HIV in the future would also be mothers of young children. Most of these women would be unmarried and would have the primary responsibility for the care of their children.

According to Broun (1999), women with HIV-infected children experience a particularly tough predicament. Most of the mothers Broun (1999) saw in therapy, expressed feelings of having failed as a mother because they could not protect their children from the horrors of this illness. Broun (1999) stated that the mothers who wanted to keep their own and their children's HIV-status a secret, felt obliged to warn their children not to let anyone come into contact with their blood, should they hurt themselves. Protecting their children as well as those around them was therefore a double burden for these mothers. According to Broun (1999) these mothers feared that their children would be rejected and hurt because of stigmatisation.

In the literature, children were perceived by HIV-positive mothers as sources of support as well as sources of stress. Kaleeba (cited in Withell, 2000) confirmed that anxiety about children and their future care appears to be universal to all HIV-positive mothers, regardless of race. In certain studies HIV-infected mothers reported increased conflict with their children (Andrews et al., cited in Hough, Brumitt, Templin, Saltz & Mood, 2002) as well as more antagonism toward their children (Semple et al., cited in Hough et al., 2002). According to Kotchick et al. (cited in Hough et al., 2002), there is some evidence to suggest that upholding a healthy relationship with one's children and monitoring their outside activities may be problematic for HIV-infected mothers and that numerous factors,

such as physical illnesses, emotional distress, lack of social support and substance abuse may be implicated. Hudis (cited in Hackl et al., 1997) reported that adolescents of mothers with AIDS often exhibit destructive behaviours including criminal activity, drug use and pregnancy.

Hough et al. (2003) stated that the psychosocial adjustment of a child of an HIV-infected mother is influenced by the intensity of the mother's emotional distress, which itself is affected by the mother's level of social support, HIV-related stressors (i.e. physical symptoms) and coping behaviour. Hough et al. (2003) found in their study that the greater the level of distress, the more child adjustment problems as accounted by both mother and child. According to Hough et al. (2003), the results of their study can be added to a growing body of literature on the direct impact of HIV-associated stressors on child adjustment, parenting skills and parent-child relationships. Sowell et al. (1999) emphasised that even when other family members are not infected, the woman's illness can drastically disrupt the family.

Notwithstanding the responsibilities and emotional distress associated with being an HIV-positive mother, a number of studies have found that the presence of dependent children can encourage a positive attitude to life and increase coping skills (Withell, 2000). Withell (2000) stated that women's reliance on children for support may again place significant stress and responsibility on vulnerable children who may be HIV-positive and lack adequate support themselves. Should the woman be a single parent, her illness can leave children orphaned, necessitating intervention by other family members or social services organisations (Withell, 2000).

Murphy et al. (2000) and Sowell et al. (1999) emphasised that a consistent finding of research studies is that social support is a vital resource for HIV-infected women with children, for the reason that it alleviates psychological distress commonly experienced by these women. Consequently, mothers with HIV/AIDS cannot be helped or treated in isolation from their children and families.

5.2.4 Summary

It is clear that insufficient knowledge exists about specific psychosocial needs and concerns of HIV-infected women, with regard to, inter alia, their healthcare, supporting and caring for their children and partners, their financial status, and their sense of future.

In the literature it is emphasised that healthcare services and psychosocial support are essential for improving quality of life for disadvantaged women with HIV/AIDS and their families. These support services should address key social issues such as poverty, interpersonal power relations, violence, and substance abuse, as well as coping with numerous family and caregiving responsibilities that women with HIV/AIDS have to face daily.

6. Coping with HIV/AIDS

Sowell et al. (1999) stated that coping is one of the most important psychological factors that account for individual differences in adaptation to difficult life situations such as HIV/AIDS. They argued that coping is a crucial issue for women with HIV/AIDS, because they are generally underprivileged and resources that are known to support effective coping, inter alia money, education, and social support, are deficient. Springer (cited in Sowell et al., 1999), like many other writers, emphasised that the great majority of women infected with HIV are very poor, are from minority groups, and must use great amounts of energy daily to satisfy the survival needs of their children and other dependants. Therefore, women are primarily vulnerable and unprepared to handle the demands of HIV infection owing to insufficient socio-economic resources that support effective coping (Sowell et al., 1999). According to Leenerts and Magilvy (2000), stigma also adds to the emotional distress of HIV-infected women and perceptions of stigma influence coping processes.

6.1 Coping strategies and effect on health

In the literature different coping strategies used by HIV-infected women are discussed, ranging from denial and distancing to more problem-solving coping styles. According to Folkman et al. (cited in Hough et al., 2003), HIV-related stress affects emotional adjustment, mediated by two categories of coping behaviour: 1) detachment coping (e.g., distancing, keeping feelings to self, cognitive escape-avoidance), and 2) involvement coping (e.g., plan-based problem solving, seeking advice and information, positive reappraisal) (p.645). In Folkman's model stress was positively related to detachment, which led to an increase in depressive symptoms, but was not directly related to involvement (cited in Hough et al., 2003). According to Simoni and Ng (2000), individuals using more problem-focused strategies show lower levels of psychological distress subsequent to life traumas compared to those favouring emotion-focused coping styles, such as detachment. These writers pointed out that effective problem-focused strategies can include rational actions, help-seeking behaviours, cognitive restructuring, religious activities, and humour. They stated further that emotion-focused strategies correlating with higher symptom levels include avoidance of cues associated with trauma and isolation. Olley (cited in Galloway, 2003) stated that the stress associated with an HIV-diagnosis could trigger unhealthy coping mechanisms, which may lead to further physical and mental breakdown.

In the study conducted by Rose and Clark-Alexander (1996), the HIV-infected women participants used confrontive, passive and emotive coping styles when dealing with stress in their everyday lives. According to these writers, this supports the theory suggested by Folkman et al. that people are inclined to use both problem-oriented (confrontive) and affect-oriented (emotive and passive) coping approaches to manage stressful situations. Rose and Clark-Alexander (1996) found that the most significant relationships were between confrontive coping and passive coping with physical quality of life. According to Rose and Clark-Alexander (1996), women with better physical well-being may be able to deal better with problems in a confrontive and problem-oriented way. On the other hand, women may cope in a more passive manner when they are feeling better physically.

According to DiPalma (cited in Simoni & Ng, 2000), avoidant coping, described as creativity and an ability to fantasise, correlates with fewer psychological symptoms, signifying that certain types of avoidance can be helpful. Nevertheless, when avoidant coping is defined as denial or withdrawal, it correlates with higher symptom levels (Frazier et al., cited in Simoni & Ng, 2000). Heath and Rodway (1999) stated that denial is a common defence mechanism used, mostly in the asymptomatic phase of the illness.

In contrast to the more harmful effects of avoidance and passive-emotive coping styles, taking an active-behavioural approach appears to be the most effective means of handling a positive diagnosis. The use of active problem-focused strategies has been associated with reduced levels of psychological distress, anxiety and depressive symptoms, and positively associated with self-esteem (McNair et al., cited in Hough et al., 2003). The participants in Withell's study (2000) described constructive living activities, such as sustaining optimum health, seeking treatment without delay, maintaining economic activities, facing reality, setting goals and educating or assisting others, as positive coping tactics which enhanced their quality of life. Most of the participants in this study were single mothers and because of lack of financial support they had no choice but to pursue some type of financial venture when they were physically not too ill. According to Withell (2000) these activities raised much needed income for rent, food and other basic necessities, but also upheld a sense of purpose, and provided a distraction from dwelling on thoughts of AIDS. These reasons for working were also cited within the "being active" category in a study conducted by Gloerson et al. (cited in Withell, (2000).

Sowell et al. (1999) stated that even though some women are inclined to use passive strategies, for instance avoidance, others actively cope with their illness notwithstanding the lack of resources needed to effectively deal with the illness. Key active strategies identified in various research studies included the use of spiritual activities focusing reliance on a higher power, managing the illness and promoting health, seeking social support from family, friends and other HIV-infected women, and focusing on the needs of others (Sowell et al., 1999). Sowell et al. (1999) stated that the type of coping strategies

used by the HIV-infected women participants in these studies were significantly related to the level of emotional distress and psychiatric problems they experienced.

In the study conducted by Hough et al. (2003), HIV-associated stressors were observed to exert a negative effect on the mother's ability to cope effectively. They found that the greater the severity of the mother's symptoms, the greater the use of passive tension-reducing coping behaviours such as crying, yelling and excessive eating, sleeping and daydreaming. The results of this study were consistent with a number of studies showing that emotional expression and fantasy are significantly related to greater anxiety, depression and mood disturbance in HIV-positive women. Lazarus et al. (cited in Hough et al., 2003) suggested that emotion-focused coping might be the more common form when events and circumstances are stressful and not perceived as changeable.

Hough et al. (2003) found that maternal social support had a strong, positive effect on the use of active meaning-making coping, which resulted in decreased emotional distress in the mothers. These results are comparable with findings from other studies pointing to the use of problem-focused coping strategies as a significant predictor of quality of life (Swindells et al., cited in Hough et al., 2003), decreased psychological distress (Namir et al., cited in Hough et al., 2003), and fewer symptoms of depression (Fleishman et al., cited in Hough et al., 2003). In the literature it is clear that the use of passive-avoidance coping strategies were positively associated with more suffering, whereas the use of active-problem-focused strategies, such as spiritual activities, self-care and generally managing the illness, were negatively associated with physical and emotional distress.

6.1.1 Spirituality and coping

According to Sarna et al. (1999), overall quality of life may be enhanced by the experience of dealing with a life-threatening illness, as patients prioritise and re-evaluate what is important to them. Relf (cited in Withell, 2000) stated that spirituality frequently increases in significance for HIV-infected women, and that contemplation on the meaning of life can

lead to spiritual enrichment. In a phenomenological study Coward (cited in Sarna et al., 1999) noted that women expressed the themes of “having a purpose and making a difference” and of AIDS being an “opportunity”.

Harrison (cited in Withell, 2000) described an apparent paradox whereby a diagnosis of HIV changed several people’s lives for the better, “through transcendence of suffering, they discovered a renewed purpose in life and received strength from God” (p.236). Spiritual beliefs were an important coping resource for more than half of the HIV-positive women participating in Withell’s study (2000). These participants’ Christian faith was a powerful source of strength and hope and had the capability to elevate an individual from the point of suicide to belief in an enduring purpose in life.

According to Gaskins (1999), women often use prayer as coping mechanism to deal with an HIV-diagnosis. Simoni and Ng (2000) stated that prayer and rediscovery of what is important in life tend to be the most prevalent coping responses for women with HIV/AIDS, followed by positive coping strategies such as seeking information or making plans. Kaplan et al. (1997) also found that prayer and personal rediscovery, namely finding new meaning in one’s existence, were the most prevalent means of coping. Lindegger and Wood (1995) substantiated that a sense of self-control and purpose or spiritual meaning have been shown to be associated with better results in terms of coping with HIV/AIDS.

6.1.2 Self-care as coping strategy

In the literature, self-care is described as a key tool for managing the physical and psychological affects of HIV/AIDS. In the study conducted by Leenerts and Magilvy (2000), self-care and health had a conceptual fit in the narratives of participants. According to Leenerts and Magilvy (2000), passive coping processes of distancing and avoidance do not support self-care practices because women may avoid the diagnosis and may not seek healthcare until symptomatic. These writers stated further that self-care

attitudes and practices became gradually more important for the women participants in their study as they came to accept their diagnosis.

Leenerts and Magilvy (2000) stated that women participants who experienced a loss of self failed to engage in proactive self-care or coping strategies. They explained that a loss of self left women powerless to protect their health and as a result, some of them did not engage in, inter alia, sexual self-care and protection. Leenerts and Magilvy (2000) reported that histories of abuse and victimisation were common in the lives of the participants in their study, and that this provided a formidable barrier to self-care and effective coping. They stated further that abuse damaged women's self-images and left them detached from self-care. They also found that women who engaged in substance abuse did not practise good self-care.

In the study conducted by Hudson et al. (2003) distressful symptoms, particularly symptoms of depression, were significantly related to self-care activities. The more psychological distress participants experienced, the less they engaged in self-care activities. Ragsdale and Morrow (cited in Hudson et al., 2003) found that higher physical symptom scores were also associated with lower self-care and quality of life. Sarna and colleagues (cited in Hudson et al., 2003) concluded that anxiety about one's illness, pain control and fatigue management restrain coping processes and may leave HIV-infected women susceptible to disruptions in quality of life. Hudson et al. (2003) emphasised that their research findings pointed in particular to self-care activities, rather than domestic activities, as the component of functional status and quality of life is affected by symptom distress. Leenerts (1999) observed that when HIV-positive women experienced caring and actual support in utilising resources for coping and self-care, they began to care for themselves. "When women were taught self-care skills they became empowered and motivated to engage in self-care practices" (Leenerts, 1999, p.15).

The study conducted by Boonpongmanee et al. (2003) on self-care in pregnant women with HIV reported that learned resourcefulness, which has been labelled as an enabling coping skill, is the strongest predictor of self-help and health-promoting behaviours.

Learned resourcefulness has been defined as personal skills that are utilised to manage the adverse effects of certain internal processes, including emotions, cognitions or sensations, in order to function effectively in daily activities (Rosenbaum, cited in Boonpongmanee et al., 2003). These writers stated further that learned resourcefulness could serve as a repertoire of coping skills for women with HIV to help them manage symptoms of depression and perform self-care. Zauszniewski (cited in Boonponmanee et al., 2003) found that individuals with high scores on learned resourcefulness showed higher adaptive functioning scores than those with low scores.

Research studies also found that interaction with other HIV-infected women was a significant resource for developing self-care skills. In addition, those women who were members of peer support groups seemed to be better informed of accessible resources and various options for coping with the illness (Christofides, 2000; Sowell et al., 1999). Thus, many writers have advocated for interventions that incorporate all dimensions of health, enhancing the physical and psychological well-being of HIV-infected women that could increase self-care practices and coping in general (Hudson et al., 2003).

6.2 Summary

Research findings have shown that providing HIV-positive women with the coping skills to deal effectively with the stress and symptoms associated with their illness may decrease social isolation and enhance their general physical and mental well-being (Vosvick et al., 2003). Attaining these skills is especially vital for disadvantaged women of colour, who are at risk for higher levels of psychosocial distress compared to most of their white counterparts. Therefore, assisting women with HIV/AIDS to develop more adaptive problem-focused coping strategies, such as self-care, a deeper spiritual awareness, social skills and general skills in managing the illness, can decrease psychological distress and enhance their overall quality of life. These coping mechanisms can be taught and strengthened through social support programmes and counselling services.

Hough et al. (2003) found in their study that coping was only one of the factors impacting on quality of life, since a mother's level of social support continues to have a direct influence on her level of emotional distress even after accounting for coping behaviour. According to them, these findings suggest that social support is imperative, both directly and indirectly, through its relation with active meaning-making coping, and imply that HIV-positive women may need help managing the sensitive issues of secrecy and stigma to allow for the utilisation of obtainable social support. According to Lindegger and Wood (1995), social support is especially important for women with HIV/AIDS because of the stigma associated with AIDS in comparison with other chronic or terminal illnesses. He also emphasised that social support (emotional, informational and practical) emerges as an important enhancer of positive coping with HIV.

7. Women's needs for psychosocial support and care

To provide effective support programmes for women with HIV/AIDS, it is essential to determine what their specific problems and needs are within their specific living environment, and at different stages of their illness condition. In the study conducted by Heath and Rodway (1999), the responses to what was needed by respondents at the time of diagnosis pointed strongly to a need for information, and for someone to listen to their concerns and just be there for them. These women expressed a wish to meet other HIV-positive women and the need for women counsellors was also mentioned. According to Heath and Rodway (1999) the need for counselling prior to HIV testing, as well as particular sensitivity towards the woman's need for emotional support and information at the time of diagnosis, are two issues of which both health practitioners and policy makers should be aware.

In Withell's study (2000) participants, particularly at the point of diagnosis or widowhood, frequently cited the helpfulness of counselling and support from NGOs. Withell (2000) stated that from early feelings of shock and desperation, the participants had been enabled to acknowledge their situation and change these emotions into positive and

constructive determinations to survive. The findings on the AIDS widows highlighted the importance of health workers also being aware of the "two in one" or the double loss that these women experience (Heath & Rodway, 1999). The double loss means the loss of a husband or partner through death as well as the loss of their own lives.

Leenerts and Magilvy (2000) reported that the participants in their study expressed concern about their ability to convey their own needs. They stated further that one of the reasons for this concern was a need to be taken seriously by healthcare providers. According to Goicoechea-Balbona et al. (2000), the HIV-infected women in their study reported a need for therapists or health counsellors who specialised in treating HIV/AIDS individuals, and who had the knowledge and sensitivity to deal with the many distresses caused by the illness. Therefore, for a health professional or worker to offer effective care and assistance to a woman with HIV/AIDS it is vital to understand her specific circumstances, by knowing how she feels and what her real needs are.

Hough et al. (2003) found that mothers with HIV/AIDS have additional stressors and needs that warrant special attention. Their research showed that children with HIV-infected mothers had significantly more adjustment problems and therefore these writers suggested that a child assessment component should be included in the care protocol of HIV-positive women. They stated further that in addition to programmes that evaluate both the mother's and child's need for continuing social support, HIV-positive mothers and their children are in need of interventions that particularly address the development of effective coping skills. Segurado, Miranda and Latorre (2003) also emphasised that psychosocial assistance and support for raising children must be regarded as fundamental aspects of provided care.

In addition to emotional support, informal others or healthcare workers can assist with practical and financial needs as well. Ciambrone (2002) stated that depending on the stage of their illness, women with HIV/AIDS could require help with activities of daily living, such as toileting, bathing and feeding, as well as instrumental activities of daily living, such as grocery shopping, housekeeping and transportation. According to Segurado

et al. (2003), nutritional care and oral health issues should not be underrated either in a comprehensive HIV/AIDS care approach. These writers stated that such issues might aid in promoting health and improving immune status, as well as represent important supporting measures in raising women's self-esteem.

Ward and Seals et al. (cited in Leenerts & Magilvy, 2000) stated that many of the socio-psychological concerns and distresses of low-income women with HIV/AIDS, such as stigma, loneliness, and depression, cannot be dealt with without adapting and improving existing social services. According to Morokoff et al. (1997), it is of the utmost importance to reduce social isolation among women with HIV/AIDS. De Marco (cited in Leenerts & Magilvy, 2000) stated that, "what is unique about women living with HIV/AIDS is that a life-threatening diagnosis or support of peers or healthcare professionals or both often served to break their silence and mobilise them to action in the form of self-advocacy" (p.72). Ciambrone (2002) discussed findings from studies examining the relationship between social support and well-being for women with HIV/AIDS. She reported that social support is a key predictor of quality of life (i.e. daily functioning, physical and mental health), positive coping, higher levels of life satisfaction, and positive self-esteem.

Many writers emphasised that there exists an urgent need for improved psychosocial support and healthcare services for the growing number of disadvantaged women with HIV/AIDS (Burke, Cook, Cohen, Wilson, Anastos, Young, Palacio, Richardson & Gange; 2003). According to Goicoechea-Balbona et al. (2000), in making HIV-related healthcare services accessible to low-income women, the details of service delivery should be women-cultural-specific. Examples of these services are: on-site and in-home child care; relief care for children with AIDS; affordable public transportation to the service site; housing and food programmes for HIV-infected women and their families; payment issues for medical treatment; the availability of psychosocial counselling and support groups; legal aid; networking; and ways to protect confidentiality (Goicoechea-Balbona et al., 2000, p.32). In the literature it is emphasised that resources, healthcare programmes and support services that are accessible and are effective by focusing on the real concerns and

needs of HIV-infected women, can contribute to physical and mental well-being, and thereby enhance their psychosocial functioning and quality of life in general.

Therefore, further research studies should be conducted evaluating women's satisfaction with HIV/AIDS care and support, which will contribute to much needed information about women's needs and healthcare experiences, including identification of potential barriers to utilisation of services and treatment.

8. Conclusion

Although women and HIV/AIDS as a field of study has received more attention in the last few years, many writers have pointed out that the needs and distress of particularly disadvantaged women are not being effectively addressed. Research has shown that this is a major medical and social problem, which raises particular issues of care and support for disadvantaged HIV-infected women with children. Many writers emphasised that the majority of women with HIV are disproportionately affected; they are women of colour, live in poverty and are single heads of households with young children. Taylor (cited in Murphy et al., 2002) stated that lower socio-economic status is often associated with poorer health and lower levels of healthcare utilisation.

Several issues affecting women's ability to respond positively to their illness and stay healthy are based on women's historical role in society, inter alia, expectations and responsibilities that women have to meet within the context of the home, family and community. Sowell et al. (1999) stated that HIV-infected women must simultaneously deal with a life-threatening illness, as well as a range of social issues such as victimisation, housing, food and employment. Having not only to manage their own illness, these women usually have to deal with their role as caregivers for their sick partners and children (Segurado et al., 2003). As a result, HIV infection does not become the first priority for these women, because of the fact that their basic needs have not been met (Sowell et al., 1999). This double-bind situation presents a great challenge to the

healthcare system as well as the women (Gaskins, 1999; Sowell et al., 1999). Cates et al. and other writers (cited in Hackl et al., 1997) stated that development of effective support services and care is particularly challenging for impoverished women with children, for whom HIV infection is but one of many life stressors.

Goicoechea-Ballbona et al. (2000) emphasised that gender inequality has resulted in the lack of development of gender-specific services for low-income women with HIV/AIDS to combat and manage their illness on a physical and psychosocial level. Sowell et al. (1999) stated that although women face many of the same devastating physical manifestations of HIV/AIDS as men, they also have unique bio-psychosocial issues related to being HIV-infected that should be studied and addressed. From the literature it is clear that the majority of women living with HIV/AIDS are in need of support groups or individual therapy/counselling to deal with the physical progression of the illness, their psychological distress, such as depressive symptoms, hopelessness, anxiety, and loneliness, as well as the stressors and strains within their daily lives, such as poverty, violence, and family responsibilities.

According to Segurado et al. (2003) the ultimate goal of medical care and psychosocial support should be to increase the duration and quality of women's lives. In the literature it is emphasised that a range of biological, psychological and social issues, impacting on quality of life, determine the overall health and well-being of women with HIV/AIDS. Segurado et al. (2003) stated the following:

> In this context, one should acknowledge that women living with HIV/AIDS have specific needs for care that must be addressed by policies, programs and practices. These are frequently multiple and complex, since these women are often faced with socio-economic stressors that may have a negative impact on physical and mental well-being. A comprehensive approach to care is therefore necessary, one that is able not only to deal with the clinical aspects of the disease, but also to provide opportunities for psychosocial assistance. (p.90)

Therefore, integrated approaches to HIV treatment that provide quality medical and mental healthcare as well as social support for disadvantaged women/mothers living with HIV/AIDS should be the main objective for healthcare providers/institutions. To achieve this objective, extensive research studies will have to be conducted on how disadvantaged women from different cultures experience their illness, thereby to gain knowledge and deepen understanding of how these women live their lives with HIV/AIDS, and what their specific and unique distresses, concerns and needs are.

Sources for references used in the above literature study are included and listed in the reference list of the main document (see References, p.292).

Addendum B

Informed-consent form
Vorm vir oorwoë toestemming

Beste Deelnemer

Hiermee wil die navorser, Elsa Herbst, u graag versoek om deel te neem aan ‘n navorsingstudie wat ondersoek instel na die psigologiese besorgdhede, probleme en behoeftes wat vroue wat HIV + is, ervaar. Indien u bereid is om aan hierdie studie deel te neem, sal die navorser graag ‘n onderhoud met u wil voer. Die onderhoud sal ongeveer drie uur duur en sal plaasvind in ‘n privaat plek en op ‘n tyd wat vir u geskik is. Die onderhoud sal op band opgeneem word.

Tydens die onderhoud sal vrae gestel word oor probleme en behoeftes wat u tans ondervind, asook hoe u daagliks funksioneer en lewe. Sommige van die vrae wat gestel word, sal egter persoonlik wees en kan onaangename herinneringe of gevoelens meebring. U moet asseblief kennis neem dat u die onderhoud te eniger tyd kan beëindig en dat u tydens die onderhoud kan weier om spesifieke vrae te beantwoord. Indien u van die studie onttrek, kan u vra dat al die data wat oor u versamel is, dit sluit die bandopnames en die transkripsies van die bande in, vernietig word. So ‘n versoek sal deur die navorser uitgevoer word.

Om die vertroulikheid van die navorsingsmateriaal te verseker, sal geen name op die onderhoude of vraelyste geplaas word nie. Elke deelnemer sal gevra word om ‘n kodenaam te kies, en daar sal ‘n lys saamgestel word om aan te toon watter deelnemer met watter kodenaam ooreenstem. Slegs die navorser en haar studieleier sal tot enige van die data toegang hê, wat die lys met kodename, die bande en die transkripsies insluit. Die lys met kodename, bande en transkripsies sal in ‘n toegesluite kas in ‘n kantoor by die Stellenbosch Hospice gebêre word.

Alle inligting sal dus vertroulik hanteer word. Verslae oor die studie, dit sluit artikels in, sal nie enige ware name noem nie. Beskrywings van alle persone sal verbloem word sodat hulle nie herkenbaar sal wees vir enigiemand anders wat die studie lees nie. Daarom sal geen stuk inligting wat deur die studie versamel is op enige manier met enige spesifieke persoon of familie verbind kan word nie. Die bande waarop die onderhoude geneem word en die lys wat die name en kodename bevat, sal ook na die voltooiing van hierdie studie vernietig word.

Indien u vind dat vrae wat tydens die navorsingsonderhoud gestel word, pynlike of onaangename herinneringe of gevoelens oproep, en u sou met iemand hieroor wil praat, kan die navorser u verwys na ‘n persoon of organsisasie wat u kan help. Verder vertrou die navorser dat die onderhoud interessant en nuttig sal wees vir elkeen wat aan die studie deelneem.

Indien u daarin belangstel om aan hierdie studie deel te neem, lees asseblief die volgende verklaring en teken hieronder.

Ek begryp dat deelname aan hierdie studie vrywillig is, en is bewus van die moontlike risiko’s, voordele en ongerief verbonde aan my deelname. Ek aanvaar dat ek vrylik vrae kan vra, kan weier om vrae te beantwoord, en dat ek ‘n sessie te eniger tyd kan beëindig. Ek begryp ook dat indien ek enige vrae of probleme het wat hierdie navorsing betref, ek die studieleier van hierdie navorsingsprojek, Dr Lou-Marie Kruger by 808 3460, kan kontak.

_____ _____

Handtekening van deelnemer **Datum**

Addendum C1

Interview schedule

A. Socio-demographic items

1. Age: _____
2. First language: _____
3. Marital status / relationship status
   - Married _____
   - Live-in lover ____
   - Separated _____
   - Divorced _____
   - Widowed _____
   - Never married ___
4. Education:
   - Primary School Std: ___
   - Secondary School Std: ___
   - Tertiary education Qualification: _____
5. Do you work for an income?

   If yes:
   - What type of work: _____
   - Hours per day: _____
6. Monthly household income: R _____
7. Number of children: _____
8. Age of children:
   - 0 - 5 years number: ____
   - 6 - 12 years number: ____
   - 13 - 18 years number: ____
   - Older than 18 years number: ____

B. Health-related items

1. HIV-status of children:
   - How many HIV-positive: ____
   - How many HIV-negative: ____
2. Time since HIV-diagnosis (of mother) in months: ___
3. Diagnostic categories:
   - Asymptomatic: ___
   - Symptomatic: ____
   - AIDS: _____
   - If symptomatic, name illness symptoms: _____
     _____
4. HIV risk categories:
   - Heterosexual sex: _____
   - Rape: _____
   - Drug use only: ____
   - Transfusion: _____
   - Unknown: _____

C. Psychosocial items

1. Emotional response:
   - How did you feel after hearing that you were HIV-positive?
   - What did you think after hearing that you were HIV-positive?
   - What did you do after hearing that you were HIV-positive?
2. Disclosure:
   - Have you discussed your diagnosis with anyone?
   - Who was the first person you told and why?
   - What has been the response of the people you've told?
   - Have you told your children?
3. Intimacy and support:

- Do you have an intimate relationship right now?
- Do you get support from your partner? If yes, how does he/she support you?
- How do you feel about the support / lack of support you receive from him/her?

**Since you and your partner are both positive, how often do you discuss your status?

4. Affect and coping:
   - Could you describe an average day since you were informed of your HIV-status?
   - How are you dealing / coping with the diagnosis on a daily basis?
   - What is the hardest part of having HIV?
   - What helps you most in dealing / coping with HIV?
5. Future concerns and plans:
   - What is your biggest concern?
   - What are you most afraid of?
   - What do you hope for?
   - What do you feel might help you cope more effectively?
   - Where does HIV rank in the order of other things you have to deal with in your life?
   - What are your expectations now?

**If applicable

Addendum C2

Onderhoudskedule

A. Sosiodemografiese items

1. Ouderdom: _____
2. Huistaal: _____
3. Huwelikstatus / verhoudingstatus:
   - Getroud ___
   - Woon saam met liefdesmaat ___
   - Woon apart van gade ___
   - Geskei ___
   - Weduwee ___
   - Nooit getroud nie ___
4. Opvoeding:
   - Laerskool St: _____
   - Hoërskool St:_____
   - Tersiêre opvoeding Kwalifikasie: _____
5. Doen u werk vir ‘n inkomste? ____

   Indien ja:
   - Watter tipe werk: _____
   - Ure per dag: _____
6. Maandelikse huishoudelike inkomste: R _____
7. Getal kinders: _____
8. Ouderdom van kinders:
   - 0 - 5 jaar getal: ___
   - 6 - 12 jaar getal: ___
   - 13 - 18 jaar getal: ___
   - Ouer as 18 jaar getal: ___

B. Gesondheidsverwante items

1. MIV-status van kinders:
   - Hoeveel MIV-positief: ___
   - Hoeveel MIV-negatief: ___
2. Tydsverloop sedert MIV-diagnose (van moeder) in maande: ___
3. Diagnostiese kategorieë:
   - Asimptomaties ___
   - Simptomaties ____
   - VIGS _____
   - Indien simptomaties, noem siektesimptome? _____
     _____
4. MIV-risikokategorieë:
   - Heteroseksuele seks ___
   - Verkragting _____
   - Slegs dwelmgebruik ____
   - Oortapping _____
   - Onbekend _____

C. Psigososiale items

1. Emosionele reaksie:
   - Hoe het jy gevoel nadat jy gehoor het jy is MIV-positief?
   - Wat het jy gedink nadat jy gehoor het jy is MIV-positief?
   - Wat het jy gedoen nadat jy gehoor het jy is MIV-positief?
2. Bekendmaking:
   - Het jy jou diagnose met enigiemand bespreek?
   - Wie was die eerste persoon wat jy vertel het en hoekom?
   - Wat was die reaksie van die mense wat jy vertel het?
   - Het jy jou kinders vertel?
3. Intimiteit en ondersteuning:
   - Het jy op die oomblik ‘n intieme verhouding?

- Kry jy ondersteuning van hierdie persoon? Indien ja, hoe ondersteun hy/sy jou?
- Hoe voel jy oor die ondersteuning / gebrek aan ondersteuning wat jy van hom/haar ontvang?

** Aangesien jy en jou metgesel albei positief is, hoe dikwels bespreek julle julle status?

4. Affek en hantering:
   - Kan jy ‘n gemiddelde dag beskryf sedert jy uitgevind het van jou MIV-status?
   - Hoe hanteer jy die diagnose op ‘n daaglikse basis?
   - Wat is die moeilikste daarvan om MIV te hê?
   - Wat help jou die meeste met jou hantering van MIV?
5. Toekomskwellinge en -planne:
   - Wat is jou grootste kwelling?
   - Waarvoor is jy die bangste?
   - Waarvoor hoop jy?
   - Wat voel jy kan jou dalk help om dinge meer effektief (beter) te hanteer?
   - Waar staan MIV in volgorde van belangrikheid op die lys van ander dinge wat jy in jou lewe moet hanteer?
   - Wat is jou verwagtinge nou?

** Indien van toepassing

Addendum D

Observational evaluation of participants

I experienced **Ann** as a friendly and open person. Throughout the interview she spoke freely about her life and problems. Ann was very ashamed of being HIV-infected and was very anxious that other people would judge, reject and victimise her and her children for having the illness. She was also particularly sad and angry because of her husband abusing alcohol, and neglecting her and her children on an emotional, practical and financial level. Ann's mother had died about a year before her diagnosis. She experienced her death as a tremendous loss. She explained that she had lost a confidante and a person who emotionally and practically supported her and her children. For me it was clear that Ann suffered many losses, the loss of her mother, the loss of her husband, and many losses accompanying the illness.

Maggie was very talkative and presented a lot of detail during the interview. At times I had to lead her back to the question presented, because she was inclined to elaborate a lot. She narrated that she felt very positive, "ek is baie sterk", and tried to handle her illness condition in that manner. Although she spoke about her inner strength that helped her cope with her illness, I sensed a deep sadness, loneliness and despair in her. It seemed as if she was concealing a lot of emotional suffering and pain. She openly spoke about her alcohol problem and it was clear to me that she used alcohol to forget about her illness condition and the consequences thereof, such as being harshly judged and rejected by others as well as the probability of an early death. Her problematic relationship with her mother caused her intense sadness and worries. It seemed that her mother was a harsh woman who could not be trusted with her secret of being HIV-infected. This she experienced as a great loss.

I experienced **Mariana** as a very reserved, sad and anxious person. She did not speak easily and struggled to answer most of the questions. Throughout the interview she

looked very despondent and cried frequently. Although she denied that she had an alcohol problem, I was aware that she abused alcohol on a daily basis. This information was given to me by welfare personnel who managed her welfare grant. Welfare had also put her two children in her mother's care because of her alcohol problem and this made her feel extremely sad and worthless. Her greatest wish was to get her children back and to be able to care for them herself. She never spoke to any person about her illness and it was clear to me that she was extremely lonely. Rejection by close family members, especially her mother, made her feel like an outcast and intensified her despair and loneliness. Mariana lived in poverty with a very abusive partner. I experienced a sense of hopelessness and powerlessness throughout the interview, because of Mariana's difficult life, her numerous problems, and lack of support, and most of all the small chance for change or improvement. It was clear that HIV was only one of many distresses in her life and that all of these distresses had a detrimental influence on her well-being and functioning.

During the interview **Joeyce** showed a great need to share her feelings and thoughts with me. Her language use was very descriptive and unique and her stories intrigued me. She openly spoke about her life and showed no inhibition about sharing very personal and private information. Although she seemed to be a jovial person, she experienced intense sadness and despair in her life. At times during the interview she seemed very confused and at a loss about what she wanted to convey to me and it seemed that she felt the same about her future, her illness condition and coping with life in general. Joeyce was visibly very ill, she moved slowly, was very thin and her hands shook constantly. Her alcohol abuse problem, which she described in detail, had a detrimental effect on her physical condition. In the interview I felt intense sadness for this young woman, only 26 years of age, being extremely ill, experiencing so much pain and suffering, and with little prospect of a future life.

Hester I experienced as a very honest and dear person. She had a gentleness about her that immediately evoked feelings of warmth and compassion in me. She was physically petite and very beautiful and I thought that if her life circumstances were different with

more opportunities, all of these personal attributes could have meant living a different life than the one she knew. Not only was she very symptomatic, but she also had to care for a very ill daughter and partner with HIV. She lived with her partner, daughter and son in very poor circumstances, she struggled to make ends meet, and was in constant physical agony because of her illness symptoms. Talking to her made me realise that it is impossible ever to comprehend the suffering and pain that most women with HIV/AIDS have to endure daily. What amazed me was the emotional resilience she showed even though she had to cope with so many distresses. She strove to keep herself emotionally strong and positive, because she believed that it was the only way to conquer the illness. I sensed in her a battle between despair and hope. Nevertheless, it seemed that hope, her inner strength, and her faith kept her going. Hester, like most of the other women, yearned for a connectedness with her mother. Hester's mother was emotionally distant from her and this caused her to feel extremely unsupported, alone and rejected. I felt extremely sad for these women, but also thankful for the mother that I have, with whom I can share everything because of her unconditional love. I thought that should I ever be diagnosed with HIV/AIDS, she would be the first person I would share it with.

I experienced **Rosy** as a quiet, humble and very reserved person. She did not speak easily and therefore I had to probe her at times, by repeating questions and asking the same question in a different way. I experienced this interview as more difficult than the previous ones. As the interview progressed, she became more relaxed and probably more trusting of me as a person. Rosy distanced herself from others, as she distanced herself from me in the interview, and mainly lived for her young daughter who was also HIV-infected. She felt very rejected and judged by people and there was no adult with whom she could share her problems or discuss her illness. Her husband abused alcohol and drugs and gave her and their daughter very little support. It was clear that she yearned for love and acceptance from others. Throughout the interview I sensed her extreme loneliness, hopelessness, sadness and despair. She, like most of the other women, lived in poor conditions and struggled daily to feed her family. Although Rosy was not as talkative as some of the other women, her narrations were meaningful and conveyed the pain and distress she was suffering daily.

Elna was a joyful, humorous and very talkative person. She had a special gift to laugh about things, even when she shared her sorrows and hardships with me. It was a life philosophy I could personally relate to and this probably made the interview easier for me. She openly told me about all her problems, frustrations and needs. Elna and her HIV-infected daughter and partner shared a flat with many other family members. She and her daughter were harshly victimised, scolded and rejected by certain family members, which caused her a lot of emotional distress and unhappiness. She also suffered physically from illness related-symptoms that affected her womanhood negatively and also caused her to distance herself from others and to stay indoors. Elna yearned for a married and family life and she was one of the few who yearned for another child. She was generally very positive about life and conveyed that she would always hope for better health and a brighter future. Talking to Elna was an enriching and inspiring experience for me; I felt that even in the most dreaded of circumstances there was always hope for something better.

I experienced **Sonja** as a very quiet and withdrawn person. Like Rosy, she did not speak easily and therefore I had to encourage her to answer questions. I tried to avoid asking leading questions and mostly repeated questions or presented a question in a different way. For me it was a relief to hear that Sonja had a very supportive and caring mother. Her mother was the first person with whom she had shared her diagnosis. It seemed that being able to talk to her mother relieved some of her emotional distress. Nevertheless, Sonja was intensely sad because her baby boy had been taken away from her by Welfare when he was only 3 weeks old and put in a home for AIDS orphans. This was done because Sonja had attempted suicide and also threatened to kill her child. At the time of the interview her boy was already 6 months old, and she had had no contact with him for more than 5 months. At that specific time my daughter, Ella, was 7 months old and I could not comprehend being without her for a day. I felt disturbed and sad for this woman being deprived of her basic rights and needs of caring for her child even though she had threatened to hurt her child at the time when she heard she was HIV-infected. At the time of the interview Sonja said that she did not contemplate suicide any more, and

the only thing that she wanted was for her baby to come home. I sensed an intense sadness, despair and grief in Sonja for being deprived of life but especially for being deprived of her motherhood.

Sylvie was one of the participants who spoke easily and openly. I experienced her as a warm and sincere person. She conveyed a strong need to share her problems and concerns with a trustworthy person, which she did not have at that stage. Although she worked with many other women in a bakery, she experienced their conversations as lighthearted and meaningless. Because of her need to talk about her life, illness, many distresses and needs she elaborated a lot, and at times it was necessary for me to lead her back to the question asked. Nevertheless, her narrations were rich and descriptive. Sylvie was the oldest of all the participants, and in the Coloured community she would be described as a big woman, 'groot vrou', meaning that she has life experience and is a mother or grandmother of children. During the interview I felt humbled in her presence, because of her wisdom and insight and all the difficult circumstances she had to cope with in her life. She yearned for her children, who lived with her family in the 'platteland', and also yearned for a normal family and married life. She was one of the few that conveyed a need for an intimate relationship with a man, and she felt the illness deprived her of that. I sensed a deep sadness and loneliness in Sylvie regarding her life and the many losses she suffered. There was also despair and anxiety about an unsure future, and ultimately suffering and dying.

I experienced **Bertha** as a very insecure and reserved person, and throughout the interview I had to encourage her to respond to questions. It seemed as if Bertha struggled to articulate her feelings and at times she did not understand basic questions. I was not sure to what extent her intellectual abilities played a role, or if it was emotionally too difficult for her to talk about her illness. For me the interview with Bertha was probably the most difficult of all the interviews. In Bertha I sensed a deep sadness, loneliness and powerlessness. She seemed very distressed about her illness, her poor life circumstances, and her lack of support and love. She said that she did not have any

strength left in her body, ‘ek het nie meer krag in my liggaam nie’, and most probably it also meant that she felt emotionally weak and powerless.

Nossie was a woman who always tried to keep a positive attitude in her difficult circumstances. I experienced Nossie as a warm and spontaneous person who shared her feelings and experiences openly and freely with me. Of all the participants, Nossie seemed to be the one who coped with her and her daughter’s illness in the healthiest way. She was also the only participant who did not use or abuse alcohol. I admired her for her resilience and faith in herself and in God. Like many of the other women, Nossie felt very disturbed and saddened by her partner not giving her and their daughter emotional and practical support. She yearned for a good relationship with her partner and for a more intimate family life. Nossie’s baby daughter was very ill at the time of the interview. It was clear she adored her baby and I sensed an extreme sadness and grief in her for her suffering child and the chance of losing her. This was emotionally difficult for me, because of my baby girl being healthy and well, and this made me extremely thankful for what I had.

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